

BRAIN RESEARCH DISCOVERIES™

USF HEALTH BYRD ALZHEIMER'S INSTITUTE

SPRING/SUMMER 2016

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Spurred by dementia's devastating toll on her late husband, lifelong educator Dr. Sherrie Nickell is determined to fight Alzheimer's disease on several fronts.



So many, giving so much

As I read this issue of *Brain Research Discoveries*, I am struck by the overwhelming generosity of volunteers in Institute activities. Our newest member of the board of directors, Sherrie Nickell, volunteers her time, as do all board members. She advocates nationally for increased Alzheimer's research funding, shares her experience with support groups, and stages fundraisers in support of Alzheimer's activities.

Over 100 USF undergraduate students volunteer in our Discovery Research Laboratories. Our Community-Based Memory Screening program relies upon volunteer memory screening administrators. Perhaps most critical in the quest to defeat Alzheimer's are the participants who volunteer for clinical research trials. We are blessed to have so many give so much to help us fulfill our mission.

David Ettelson is a psychometrician who plays a key role in assessing cognitive functions of patients in our multispecialty diagnostic clinic. His skills are also essential in conducting the clinical drug trials in a consistent and accurate fashion.

Kevin Nash is a remarkable scientist whose work touches almost all Discovery Research Laboratory faculty members. He directs the Viral Vector Core facility, which supports projects testing genes that could benefit or worsen Alzheimer's dementia, potentially identifying new drug targets. Kevin is able to pay 100 percent of his salary from research grant funds.

Adria Dickey describes the importance of power of attorney, living will, last will and testament, and health care surrogate documents as we grow older. Unfortunately, when we need them, we are often not of capacity to validly make these decisions. Providing legal evidence of our preferences as we grow older greatly simplifies end-of-life care. I urge you to make the time to complete these important legal documents before it is too late.

On the legislative front, Congress finally passed a new budget and included a \$350 million increase in funding for Alzheimer's disease research. This brings us to almost \$1 billion of the \$2 billion in annual funding that we believe is necessary to have meaningful treatments for Alzheimer's by 2025. Please continue advising your elected representatives of how important Alzheimer's research is to you.

At the USF Health Research Day on February 19, several Byrd Institute researchers received awards for Outstanding Posters. The award winners are: Anjenet Loon (Pharmacy), Abdulah Barakat (Pharmacy), Mevin Matthew (Undergraduate), Aurélie Joly-Amado (Postdoctoral Fellow), and Leslie Sandusky (Postdoctoral Fellow).

In closing, I want to share with you our sadness that one of our most ardent supporters, Sherrill Tomasino, will be leaving us to be near her grandchildren in Ohio. Sherrill served on the original Byrd Institute board when it was a public corporation and has been chairperson of the board of directors since the Institute joined USF. She has served us remarkably well, and she spreads the word about this center of excellence wherever she goes. We will miss her greatly and wish her continued health and happiness in Ohio.

...until Alzheimer's is a memory® ■

Dave Morgan, PhD
CHIEF EXECUTIVE OFFICER



ALEX STAFFORD

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Searching for clues

Research scientist Dr. Kevin Nash believes gene therapy may help turn the tide against Alzheimer's and other diseases.

Ask Kevin Nash what he does for a living and his simple answer is, "I work on Alzheimer's research." It's a lot easier than explaining that he's experimenting with gene therapy in mice to try to thwart Alzheimer's disease and preserve brain function.

He's been conducting research like this in a lab for more than a decade and believes it holds promise, as scientists worldwide search for answers to the escalating disease that threatens to bankrupt not only families but also entire federal programs designed to help those who have exhausted their resources.

Nash, a scientist at the USF Health Byrd Alzheimer's Institute, wishes he could find a way to reverse the damage of memory loss, but for now he hopes to at least halt its advance.

"Ideally, it would be perfect if we can reverse the damage, but at the very least, if we can prevent further damage from occurring, then we could prevent further memory loss," says the 44-year-old biochemist.

An Australian transplant

Nash acknowledges a lifelong interest in science and nature that began in a small town south of Brisbane, Australia, where he grew up. He received a bachelor's degree in biochemistry and microbiology from the University of Queensland and went on to complete a doctorate in biochemistry there, before venturing to the United States nearly 20 years ago for additional studies.

He took part in HIV research before shifting his attention to studying the biology of a virus that has become an important tool for gene therapy. Since then, he has focused on gene therapy and how it might benefit people with neurological disorders. Nash worked as a research assistant professor at the University of Florida's Powell Center for Gene Therapy for five years before being wooed to join the Byrd Institute's research team by CEO Dr. Dave Morgan in 2008.

"We were lucky to get him," says fellow Byrd scientist Marcia Gordon, PhD. "Kevin is an expert in gene therapy... [and] is able to construct novel gene therapies for us to test in our animal models of Alzheimer's disease."

Nash's research involves increasing the presence of a naturally occurring protein in the brain to reduce inflammation linked to memory loss. By injecting genetic material directly into the brains of mice with conditions similar to Alzheimer's, to produce more of the desired protein, Nash hopes to protect neurons critical to brain function.

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PHOTO BY ALEX STAFFORD

Biochemist Dr. Kevin Nash and fellow scientists at the Byrd Institute search for ways that gene therapy could help fight Alzheimer's disease.





PHOTO BY ALEX STAFFORD

“I think gene therapy is promising, because if you can restore a particular gene in a person and then they permanently have that gene, they may not have to take a drug for the rest of their life.”

Kevin Nash, PhD

Searching for clues

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He’s the first to admit that working with mice has its limitations in trying to find a cure for humans. “There have been a lot of successful studies with mice, but translating that to humans has been a little more difficult,” he says. “Because the human brain is so much bigger, it’s difficult to deliver [the genetic material] to the entire brain like we can in a mouse.”

Another challenge facing Alzheimer’s researchers is understanding the “very complex” roles of the different types of cells in the human brain and how they communicate with each other, he adds. Nash is currently interested in understanding the involvement of the immune cells in the brain and how they affect the health of neurons responsible for communication among brain cells.

Gordon sees potential in her colleague’s work. “While it’s possible that gene therapy could be used in patients, it’s more likely that the gene therapy in animals can be used to find entirely new pathways that might ultimately yield a medication down the line,” she says.

Inside and outside the lab

When he’s not collaborating with most of the other Byrd Institute scientists on their varied research projects or searching for answers in his own studies, Nash escapes life in the lab by reading (science fiction), watching movies, playing with his two dogs (Jackson, a 55-pound mutt, and Karley, a 25-pound Sheltie) and modernizing a home he recently purchased with his long-time partner, Scott, an IT technician, whom he married last spring. But his passion to understand gene therapy’s potential in treating illnesses makes him eager to return to the lab.

He believes that introducing critical genes into the body that it may lack could shed light on treating not only Alzheimer’s but also other diseases as well.

“The idea is you could deliver a gene that someone is missing and if the gene fixes the problem, then they wouldn’t have to continuously have drugs or injections” to manage their illness, he says. “I think gene therapy is promising, because if you can restore a particular gene in a person and then they permanently have that gene, they may not have to take a drug for the rest of their life.”

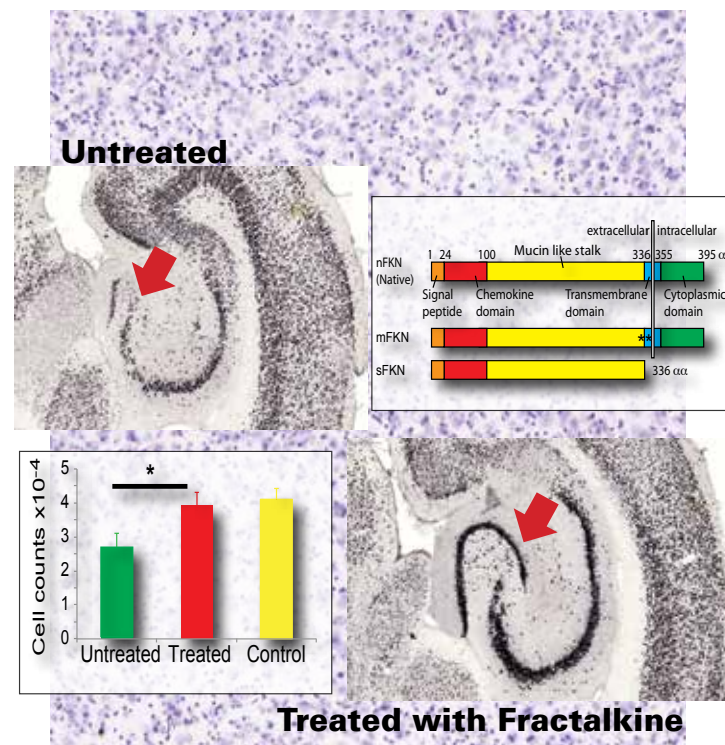
Although finding answers to Alzheimer’s, one of the most vexing diseases in the world, has been elusive to date, Nash remains hopeful that science will yield some insights.

“I think we’re getting closer, and we’re certainly getting a better understanding of what’s going on,” he says.

“Each year we’re getting more information. Maybe in 10 years we’ll have some better treatments. I wouldn’t say a cure, but maybe treat some of the problems associated with Alzheimer’s.” ■

Expression of Fractalkine in the brains of AD mice protects neurons in the mouse brain from dying.

The number of neuron cells in the brain region called the hippocampus, an area affected in AD, decrease with age in the mouse model Tg4510 (green bar on graph). Using gene therapy to increase the amount of Fractalkine in the brain, we were able to protect the neurons from death (red bar on graph; see arrows on images). Fractalkine acts on the immune cells of the brain to reduce detrimental affects of inflammation. A protection against neuron loss or brain atrophy in this model is a significant finding and suggests hope for a therapeutic treatment.



What’s your backup plan?

Planning ahead is essential for families to avoid costly and time-consuming obstacles if a primary caregiver becomes sidelined temporarily or permanently.

As an attorney who specializes in elder law, Adria Dickey frequently hears from people trying to untangle the mess of wanting to help a loved one but not having the legal standing to do so.

She knows it would have been a lot simpler if the people the callers want to help – often an ailing parent or spouse – had spelled out their wishes before being confronted with a serious health issue.

Some families are unprepared when the caregiver, often a spouse, is suddenly no longer able to provide care, and there’s no backup plan in place for anyone else to take charge when dealing with doctors, insurance companies and other service providers.

“The time and cost to spell out your wishes in advance pale in comparison to the headaches if you don’t,” says Dickey, who practices in Tampa.

She says many people wanting to care for a loved one don’t realize:

- Grown children can’t make medical, financial or legal decisions for an ailing parent without the parent’s expressed wishes in writing. These so-called advance directives include the designation of one or more health care surrogates and a durable power of attorney.
- Those same adult children can’t ask a lawyer to draw up papers granting them those privileges to help care for Mom or Dad. It has to come from their parent while they’re still mentally capable of doing so.
- The best legal documents list a succession of three people to handle medical and financial affairs, in case one or more of them are unable to do so in the future. Some families may choose different people for each of those responsibilities.
- What can be accomplished in a couple of hours with an elder law or estate planning attorney is far less costly and time-consuming than turning to the courts to establish guardianship if a loved one is no longer able to make decisions on their own behalf.

Elder law attorney
Adria Dickey



PHOTO BY ALEX STAFFORD

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Helping caregivers plan ahead

Educator and Alzheimer’s specialist Eileen Poiley, who often meets with caregivers of Alzheimer’s patients at seminars and support groups throughout the Tampa Bay area, will challenge her audience to think about what would happen if they were no longer able to care for their loved one, either permanently or just for a few weeks or months. “I understand that it’s very emotional and very difficult to have to think about that possibility,” she tells them. “But you also have to think in terms of what you can do to make sure your loved one is cared for in case something happens to you. You want that transition to go as well as possible.”

Poiley, the director of education at the USF Health Byrd Alzheimer’s Institute, knows that many caregivers devote little time to developing backup plans, because they’re too busy, they haven’t given much thought to it, or they view the prospect of not being able to care for their loved one at some point as too upsetting.

She uses a simple analogy to shift their thinking. “I say to them, ‘Raise your hand if you have car insurance.’ And, of course, everybody raises their hands,” she says. “Then I say, ‘Raise your hand if you put some effort into getting that car insurance. Did you look for a good policy? Did you make sure it’s with a reliable company? And it has

good coverage at an affordable price?’” Again, their hands go up. “And then I say, ‘Now raise your hand if you hope to use that insurance, meaning you hope to have an accident.’ No one raises their hand. So I point out to them that they’ve put forth all that effort just in case they ever need it, and that’s how I view having a backup plan as a caregiver. “I ask them what would happen if they get pneumonia for a month, or they fall and break an ankle and have to go to rehab? You may not be able to be the primary caregiver while you recuperate, and you want to make sure that there are things you’ve put in place in case you ever need it, just like with car insurance.”

Develop a caregiver line of succession

Although spouses can act as the medical surrogate for their partners, they may run into trouble dealing with insurance companies or other financial matters without a durable power of attorney, Dickey said. And if the caregiving spouse takes ill, he or she cannot designate who else can take over when dealing with a loved one’s health care providers or their financial matters, she adds. “The primary caregiver can’t appoint someone else on their

own,” she says. “It all goes back to the legal documents that the patient signed. Usually people are very surprised, because they think I’m the son or I’m the daughter, and I should be able to do this. But if they’re not the one listed on a durable power of attorney or a health care document, then they can’t,” she says.

That’s why Dickey advises her clients to list three people in a hierarchy of who will be able to step in to help, if needed. “Who’s first in line to make those decisions, and if that person isn’t available, who’s second in line, and if that person isn’t available, who’s third in line? “Sometimes it’s hard for folks to come up with those names, but I tell them it’s better for you to come up with them instead of a judge who has never met you and has never met your family, and there could be people coming out of the woodwork saying, ‘Me, me, me...I’ll do it!’ that you may not trust,” she says.

Getting started

Dickey says an elder law or estate planning attorney may need only a couple of hours to help individuals create their advance directives and would be more familiar with recent changes in the law than other attorneys. The national Elder Care Locator (www.eldercare.gov or 1-800-677-1116) can direct you to lawyers in those specialties in your community.

Poiley encourages caregivers to contact their local Area Agency on Aging to find out if they qualify for caregiving programs and services in their community, as well as benefits provided by the Veterans Administration and the Medicaid Long Term Care program. The Elder Care Locator can put them in touch with their local Agency on Aging.

Caregivers should also plan ahead by contacting home health agencies or scoping out local assisted living facilities or nursing homes as part of their backup plans, Poiley said. Attending a support group is a great way to get recommendations from other caregivers about facilities and agencies. Dickey recommends they start by reviewing facilities’ ratings by state inspectors with the Agency for Health Care Administration (www.ahca.myflorida.com).

“Find out what you like and what’s available when you’re not in crisis, because crisis management is the worst place you want to be,” Poiley advises caregivers. “And once they take these steps, they definitely feel a sense of relief that something is in place,” she adds. Dickey recommends that above all else, don’t wait. “Put it on the front burner and do it as soon as possible, because at some point, you’re likely to need it, and then it may be too late.” ■



One woman’s story

No one expected John Ray to be unable to care for his wife, Betsy, at home as she struggled with Alzheimer’s for six years. After all, John had no major health problems and even their grown children were impressed with his energy after more than 50 years of marriage.

Then, suddenly, at age 75, John suffered a brain abscess that caused stroke-like symptoms in early 2013. He died three months later of complications from a related surgery. Their daughter, Margaret Hammontree, who lived two miles away from her parents’ Temple Terrace home near Tampa, suddenly found herself as her mother’s primary caregiver while raising three children of her own, ranging in age from 8 to 19.

Although her father’s illness and death came “out of the blue,” Hammontree says she’s grateful that her parents took some important steps to ease her transition into full-time caregiving.

Years earlier, when Betsy Ray was still able to make decisions for herself, she designated Hammontree to serve as her health care surrogate if her husband was no longer able to do so. In addition, documents drawn up with a lawyer who handled the Rays’ estate planning allowed Hammontree to manage her mother’s finances. Hammontree, 48, cared for her mother at home for nearly two years before placing her in a nearby assisted living facility for memory-care patients.

Hammontree considers herself fortunate that her parents’ wishes were clear and in writing, but there were still some things that she wishes she had been better prepared for. She wasn’t sure what daily medications her mother was taking. She was able to get the list from her mother’s doctor, only to find out later that her mother had stopped taking some of the drugs on the list.

Hammontree suggests that caregivers compile a list of the dates, times and dosages of all medications a patient receives, so that whoever else steps in can pick up where they left off. A list of their allergies is helpful, too.

She also recommends that people such as her father, caring for someone at home with memory loss, take precautions for themselves “as if they were living alone.” When her father suddenly collapsed at home, her mother was unable to summon help quickly because of her dementia. A medical alert bracelet may come in handy in some circumstances, she said.

Hammontree says it’s also important for people to review at least annually whom they’ve designated to act on their behalf in medical, financial and legal matters, because their rationale may change over time. “For the most part, my parents did plan well, but nobody saw this coming and never really thought that this was something that was going to be needed,” she said.

Her advice to other caregivers is simple: “As unpleasant as it is to think about it, ask yourself, ‘If something were to happen to me today, what would be the effects of that – and what can I do to fix the things that would be a problem?’”



Caregiver Checklist

Well-meaning family members often face roadblocks and frustration when trying to take on a loved one’s medical or financial matters without adequate information. If you’re caring for a loved one with Alzheimer’s, it is especially important to take the time to compile the information below, as your loved one may not be able to remember and provide it. If someone else has to take over as caregiver, either temporarily or permanently, having the following written down can be extremely helpful.

<input checked="" type="checkbox"/> List of doctors Names, addresses, phone numbers and specialties. HIPAA privacy rules can prevent doctors from sharing medical information with family members, so make sure the health care providers have been given permission to talk to others in the family that may assume caregiving duties.	<input checked="" type="checkbox"/> Legal and financial Lawyer, banking institutions, safety-deposit boxes, documentation of prepaid funeral arrangements, veteran’s status, advance directives (including health care surrogate), durable power of attorney, living will, and estate will. Access to bills and documents related to other financial responsibilities.
<input checked="" type="checkbox"/> List of prescription medications Include prescribing physician, strength, dosage, purpose, special instructions and pharmacy.	<input checked="" type="checkbox"/> Local contacts Including relatives, neighbors, friends, clergy, lawyer, care manager and support group leader.
<input checked="" type="checkbox"/> List of over-the-counter drugs Painkillers, vitamins, supplements, herbals, etc.	<input checked="" type="checkbox"/> Local services Such as hospital preference, adult day care, assisted living or nursing facilities, home health agencies, Meals on Wheels, etc.
<input checked="" type="checkbox"/> Medical information Include all current diagnoses, other physical or health conditions, medical history, and food and drug allergies.	<input checked="" type="checkbox"/> Patient personal information This includes information to help other caregivers know your loved one better. Include information about their past, their preferences, favorite foods, favorite activities/hobbies and religion. Also describe what upsets them, how to calm them, and what makes them happy.
<input checked="" type="checkbox"/> Insurance Medical, supplemental, prescription drug, long-term care, car and property.	

Building a bigger safety net

To help more Floridians identify the early signs of Alzheimer's or other forms of dementia, the Byrd Institute is training volunteers to conduct memory screenings in their communities.



For information on establishing a Community-Based Memory Screening Program in your area, call (813) 974-4357.

Dr. Theresa Crocker, assistant director of community-based research at the Byrd Institute, conducts the fourth in a series of educational classes for memory screening volunteers with the South Shore Coalition for Mental Health and Aging in Sun City Center.

Three or four times a month, Lorraine Daniels does what she knows best: helping others. The busy retiree draws upon the skills she honed as a nurse to help people in her central Florida community get an important medical screening.

Daniels, 76, asks them a few simple questions and then gives them a pencil-and-paper screening to check their memory. Most complete the screening with no trouble.

Daniels knows that she and more than two dozen of her fellow volunteers – all working or retired nurses – are doing something worthwhile, because the people who come to see them will mark their calendars for their return visit a year later. Sometimes the memory screeners have had to create a waiting list in their retirement community, known as The Villages, about 45 miles northwest of Orlando.

“The people we see really appreciate it, and they’re surprised there’s no charge,” says Daniels, a former hospital nurse who worked with cardiac rehabilitation patients in Michigan City, Indiana.

“Sometimes a neighbor will bring a neighbor because they have a concern,” she adds. “And when we do pick up on problems people have, we refer them to their physician, a neurologist, or to the Byrd Institute, where it’s looked into further before they will get a diagnosis.”

The Community-Based Memory Screening Program was launched in The Villages in 2011 by USF Health Byrd Alzheimer’s Institute. Members of the Institute’s staff have trained volunteers to conduct similar screenings in Sun City Center, Lakeland and several communities in Tampa, including one predominantly African-American neighborhood, to help more minorities learn about and access help. The Institute plans to eventually replicate the program in various communities across the state.

“We’re taking the lead on this, which makes sense, because we are the only center like this in the state,” says Theresa Crocker, PhD, assistant director of community-based research at the Byrd Institute.

Organizers cite multiple benefits

The Byrd Institute sees several benefits to the outreach program.

“Part of the reason is to help increase the opportunity for people to participate in more prevention-focused clinical trials,” Crocker says.

“Another reason is: If we can identify people sooner who have the disease, then they can begin medication that may help preserve the function they have and slow the progression of Alzheimer’s,” she adds. “We don’t have an effective cure for Alzheimer’s yet, but we do have some medications that are more effective if they are started earlier.”

Early identification also alerts families to make sure they have valuable legal documents – designating a power of attorney and health care surrogate – along with other important paperwork, while the patient is still capable of making decisions, Crocker says.

“The program also helps to provide education and build awareness of Alzheimer’s disease,” she explains. “A lot of people erroneously believe that memory loss is a normal part of aging, which it isn’t. We want to provide education and awareness that there could be medical intervention that is helpful.”

Volunteers receive training

More than 4,000 people have been screened in the past five years by trained volunteers. Many of the volunteers, like Daniels, have medical backgrounds and understand the importance of patient confidentiality

and other health care standards. But as the program grows, so does the variety of people signing up to help out, including a financial planner, a speech therapist and a schoolteacher. All volunteers undergo a four-part training program to learn how to administer and score the standardized screening, and to provide results and individualized recommendations for next steps.

Volunteers also provide participants with a packet that includes information on frequently asked questions about Alzheimer's and recommended steps towards making the diagnosis, should that be necessary. They are also trained

“The beauty of this program is that it is community-based. It’s a community reaching out to us saying, ‘We know that this is important and we want to make it available to others, and how can we get involved?’”

Theresa Crocker, PhD

to provide basic education on how other health conditions can impact memory. “Sometimes a thyroid condition or sleep problems can affect memory,” Crocker says.

The volunteers remind participants that the screenings are not diagnostic and that only medical professionals can make a diagnosis after comprehensive evaluation. They encourage participants to share their test results with their primary care doctors. The volunteers will even fax the results to a doctor's office, if the participant signs a release.

“When they come to see us the first time, it's like they're establishing a baseline” of their cognitive skills, Daniels says. “A lot of the doctors in The Villages are aware of the results form we give each person, and they request it from their patients.”

Crocker explains that, while Medicare now covers memory screening as part

of an annual wellness exam, many primary care doctors have little time or training to do it satisfactorily during a patient's brief visit. “Usually what doctors can do in their office is nowhere near as comprehensive as what we can do with our 30-minute screening,” she says.

Community support is essential

Crocker explains that the program succeeds not only because nearly 50 volunteers have been trained to date, but also because many businesses and civic

munity reaching out to us saying, ‘We know that this is important and we want to make it available to others, and how can we get involved?’ It's certainly a program that could be implemented anywhere.”

Crocker says that the Byrd Institute has prepared a training kit to answer inquiries from other states and as far away as Europe.

Later this year, organizers hope to expand their community outreach efforts with the introduction of a mobile research unit to make some



Memory screening volunteers Andrew “Mick” Hebel and patsy monk are members of the South Shore Coalition for Mental Health and Aging.

groups are contributing essential support services.

“We’ve had requests from four different organizations in the Lakeland area that want to participate in this program however they can,” she says. “They’re opening up their buildings to use free of charge, they’re providing scheduling support and a telephone number for making appointments, and they’re providing copying machines and their own personnel to participate in the program and coordinate it.

“The beauty of this program is that it is community-based,” she adds. “It’s a com-

of the Institute’s clinical trials more accessible, by eliminating the need to travel to its Tampa campus.

In the meantime, Lorraine Daniels will continue providing memory screenings to her neighbors when she’s not playing golf or spending time with her husband of 52 years or their four grown children and seven grandchildren.

“I like to feel that if you became a nurse, you have a dedication to help others,” she says. ■

Allies on many battlefronts

Volunteers eager for medical breakthroughs understand the vital role of drug research and testing.

Jill Smith runs a busy research clinic. She hopes it gets even busier as she oversees studies involving a dozen different drugs that may help identify, delay or prevent Alzheimer's disease in its various stages.

Smith is the assistant director for clinical research at the USF Health Byrd Alzheimer's Institute, a leading scientific research and testing facility. She assists the Institute's principal investigators and coordinates the participation of volunteers in some of the latest medical research that could lead to the next big breakthrough in preventing or treating dementia.

“This is an extremely exciting time for Alzheimer's research,” she says. “We’re really starting to pick up momentum, and we’re getting that much closer to finding the next new treatment.”

The Byrd Institute is conducting several clinical trials, six of which are currently in need of volunteers. The investigational drugs have already been evaluated for initial safety and are now in studies to test their effectiveness.

Volunteers pay nothing to participate, and their overall well-being is monitored regularly throughout the course of each study. The clinical trials are typically funded by the federal government or major pharmaceutical companies and are offered at many research facilities throughout the country.

“What’s exciting about the ones that are currently enrolling at the Byrd Institute is that they cover every spectrum of memory in older adults,” Smith explains. “We have a study for people with no memory problems at all, and we have

studies for people with mild or moderate Alzheimer's.”

More than 100 participants from throughout the state are taking part in the Institute's research at any given time. Many of them chose the Byrd Institute over smaller testing sites, and Smith says that is “because we’re affiliated with both the University and the state.”

“We also understand the disease process better and can deal with issues that come up during the course of the study,” she adds. “Private research offices often do not have that same expertise, even though they may be doing research in memory loss.”

For more information, contact Smith at (813) 974-1294. ■

A4 Study

Therapeutic Intervention: Monoclonal Antibody for Beta Amyloid

Number of test sites nationwide: 60

Target number of participants nationwide: 1,000

Sponsors: National Institutes of Health; Eli Lilly

Length of study: 3½ years

Connect or “FYN” Study

Therapeutic Intervention: Fyn Enzyme Inhibitor

Number of test sites nationwide: 20

Target number of participants nationwide: 1,500

Sponsors: Yale University; The National Center for Advancing Translational Sciences

Length of study: 1 year

Engage Study

Therapeutic Intervention: Monoclonal Antibody for Beta Amyloid

Number of test sites nationwide: 150

Target number of participants nationwide: 1,350

Sponsor: Biogen

Length of study: 18 months

BAN Study

Therapeutic Intervention: Monoclonal Antibody for Beta Amyloid

Number of test sites nationwide: 71

Target number of participants nationwide: 800

Sponsor: Eisai Inc.

Length of study: 18 months

Coconut Oil Study

Therapeutic Intervention: “Brain Fuel Replacement” with Ketones

Number of test sites nationwide: 1

Target number of participants nationwide: 65

Sponsors: USF; The Anne & Leo Albert Charitable Trust

Length of study: 8 months

APEC Study

Therapeutic Intervention: BACE Inhibitor for Beta Amyloid

Number of test sites nationwide: 89

Target number of participants nationwide: 1,500

Sponsor: Merck

Length of study: 24 months

Q & A with memory evaluator Dave Ettelson, PhD

Dr. Dave Ettelson helps families get the answers they're looking for when they suspect a loved one is showing early signs of dementia. He's part of a diagnostic team at the USF Health Byrd Alzheimer's Institute, where hundreds of families come each year for insight as they plan for the future.

Ettelson, who has a doctorate in counseling psychology from the University of Southern California, has been involved in Alzheimer's research for the last four years, including the past year at the Byrd Institute, where he administers a series of tests to measure cognitive ability.

He works alongside four other specialists – in internal medicine, pharmacology, social work and geriatric psychiatry – to evaluate new patients and their brain function on several fronts. He also tests participants in the Institute's many clinical trials, to document any changes in their mental ability.

Technically he's known as a psychometrician, but don't let the title confuse you.

Q: In layman's terms, what's a psychometrician?

A: Basically, a psychometrician is a person who administers psychological tests to measure memory, other types of cognition, intelligence, mood and personality, among other things. At the Byrd Institute, the most important mental testing focus is on memory. Outside of medical care, psychometricians might also work for test publishers, credentialing boards or departments of education to create valid, reliable and fair tests for the general population.

Q: What are your duties at the Byrd Institute?

A: My duties include testing subjects in clinical research trials, assessing patients for memory problems in our C.A.R.E. clinic, and being available for community screenings when needed.

Q: How many different kinds of tests do you typically perform with someone who may be experiencing memory loss?

A: There are a large number of tests that focus on memory, but in terms of diagnosing Alzheimer's disease or other dementias, it's important to look at other areas as well. Different forms of dementia manifest different cognitive deficits, so it's important to assess not only memory but also attention, language, visuo-spatial skills, physical movement, abstract abilities, planning and organizational skills. I use an instrument at the C.A.R.E. clinic that screens for all of these things. Since mood is sometimes implicated in dementia, it's also important to include a questionnaire that assesses level of depression.

Q: Are the tests verbal? Pencil and paper? Computer based?

A: Most memory testing involves a combination of verbal interaction and traditional paper-and-pencil performance. In other words, it is important to check for both the patient's responsiveness to spoken instructions as well as an ability to draw or write. A recent trend in clinical research is to collect data on a computer tablet, and we currently do this for one of our trials at the Byrd Institute. Besides efficiency,

another advantage of the tablet is mobility; if the examiner can bring the test to the patient, he or she can favorably impact under-served populations.

Q: Are your test results all that the medical staff needs to make a diagnosis of Alzheimer's or some other form of dementia, or do they also take into account a brain scan or other factors?

A: Although psychometric tests are one piece of the investigatory puzzle, it takes several other inputs to accurately diagnose Alzheimer's disease or other dementias. This might include brain scans, blood samples, lumbar punctures, physical exams, medical and personal history-taking, and a review of currently prescribed medications.

Q: Do you have an ongoing role with patients after their initial diagnosis?

A: After a patient's initial diagnosis, my ongoing involvement depends on their goals. If they want to receive individual follow-up medical care, they either return to their primary care doctor or see one of our physicians. If they want to participate in clinical trials, I begin assessing them on a unique set of tests determined by the study sponsor. I continue to see and assess them every few months for a year or longer. Research sponsors know that rapport between the patient and psychometrician is important, so it is helpful for the same examiner to test the same patient repeatedly.

Q: How did you get into this specialized line of work?

A: Most importantly, I got into this specialized line of work because I have always loved the precision and creativity that goes into developing and administering tests. People with diverse backgrounds can train to administer tests, but often it involves some combination of knowledge in psychology and gerontology, and training in assessment. For more in-depth cognitive evaluations, it's important to have training in neuropsychology and neuroanatomy. Many patients are sensitive about being tested, so if I can get them to laugh or smile while collecting reliable data, it has been a good day! ■

Within a few minutes of talking to Sherrie Nickell, it's clear that she's well-spoken, polite and driven.

Her rallying cry to anyone who will listen – and she makes sure others will hear her message – is to help put an end to the disease that robbed her of a golden retirement with her husband, who died in June 2014 of multiple forms of dementia.

Sherrie and Bill Nickell had been married for 26 years when, in late 2012, he was diagnosed with Alzheimer's disease and two less-common forms of cognitive impairment: vascular dementia and Lewy body dementia. His health declined rapidly, and he died 1½ years later at the age of 73.

headed our way," she says. "When you run the numbers regarding the next several years, the percentage of people who are going to be afflicted with some kind of dementia is overwhelming. That's one of the reasons I feel a sense of urgency in trying to get the message out."

Another reason for her activism resonates to her core.

"I often tell people that if I had a scale and I put on one side of the scale every other bad thing that ever happened to me in my entire life, and on the other side of the scale placed the journey with my husband's illness, Bill's dementia would far outweigh everything else combined," she says. "It was the worst experience I've ever had."

become the nation's most expensive illness in recent years, surpassing cancer, heart disease and other leading causes of death.

Alzheimer's is also the only cause of death among the top 10 in the United States that cannot be prevented or cured.

That's where Sherrie Nickell, the educator, has found her niche.

Having "thoroughly researched" caring for someone with dementia and discovering that "it's much more pervasive than I realized," Nickell decided to educate others, to enlist their help in turning the corner on Alzheimer's and other forms of dementia.

"I feel as though our community – whether it's our local, state or national

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Turning passion into action

It should come as no surprise that a former school superintendent is relying on education to rally others in her crusade against dementia.

His much-younger wife had walked away from her dream job as superintendent of schools in Lakeland and surrounding Polk County in central Florida to care for him throughout his illness.

And now, at 57, she's using the painful lessons she learned firsthand to not only help others facing similar challenges but also help turn the tide against the diseases that can leave families emotionally and financially drained.

She has begun lobbying state and federal lawmakers for more research money. She offers emotional support and insight to families facing similar journeys. And this past summer, she agreed to serve on the board of directors for one of the nation's leading Alzheimer's research facilities, the University of South Florida's Byrd Alzheimer's Institute in Tampa.

"The Baby Boomer population is aging, and I feel as though we're facing a tsunami [of new Alzheimer's cases]

Raising awareness to build support

Nickell credits herself with being a fairly well-read, well-traveled person. She has a doctorate in education and worked her way up from a first-grade teacher in the Polk County School District in 1987 to the superintendent's office 23 years later.

But she's the first to admit that she was in the dark when confronted with her husband's illness and what it would entail for both of them.

"I never knew there could be more than one kind of dementia, and I never anticipated that my husband's timeline could be so short. It's been quite a journey of learning for me," she says.

She believes others who are similarly unfamiliar with Alzheimer's devastating toll would be willing to do more if they understood the scope of its grasp.

With more than 5 million Americans living with Alzheimer's disease, it has



Dr. Sherrie Nickell's late husband, Bill, and mother, Ethelyn Burnette, were on hand to celebrate Dr. Nickell's swearing in as Polk County, Florida, superintendent of schools in November 2010.

"I would encourage anyone who has a passion for helping out in this cause to donate not only their time but also their resources in any way possible. It's certainly an important cause that I think will eventually touch all of us in some way."

Sherrie Nickell, Alzheimer's activist and Byrd Institute board member

Turning passion into action

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community – needs to learn a lot more about this disease,” she says.

In January 2015, she met with state lawmakers in Tallahassee – many of whom she knew from her previous role as a superintendent – and begged them to join her bandwagon.

Last spring she flew to Washington, D.C., for the Alzheimer's Association Advocacy Forum Conference, to urge lawmakers on Capitol Hill to increase funding for dementia research.

“When you look at the amount of national funding allocated to dementia research, it's minuscule compared to the amount of funding for heart disease or cancer or AIDS research. And yet, the cost of dementia is so incredibly expensive, and it's growing exponentially,” she explains. “People in positions of authority and influence need to understand that much more attention needs to be placed on this disease – on research and on a cure.”

She's encouraged that the message of Alzheimer's advocates may be getting through.

The 2016 federal budget, recently approved by Congress and signed into law by President Obama, increases funding for Alzheimer's research by \$350 million, the largest increase ever in federal support for such research and a nearly 60 percent increase over the prior year's allocation.

Nickell's commitment is multi-faceted. She visits Alzheimer's support groups so

that she can share what she's learned with others embarking on similar journeys. She was tapped to emcee the Polk County Walk Against Alzheimer's for the past two years. And she takes calls from caregivers who seek advice or a sympathetic ear in dealing with their struggle.

“I feel compelled to do anything I can to further the cause,” she says, “whether it's helping someone in a restaurant understand how to deal with a person who has dementia and is struggling to order, or informing a medical professional who might grow impatient if he or she is unaware that a person has dementia, or speaking with a lawmaker who has the power to change some of the laws and to

increase the budget to advance research.”

Some people donate money to their favorite causes. Others donate their time. Nickell does both, knowing it may help advance research, support caregivers, or promote early diagnosis and participation in drug trials.

“I would encourage anyone who has a passion for helping out in this cause to donate not only time but also resources in any way possible,” she says. “It's certainly an important cause that I think will eventually touch all of us in some way.

“I would love to be able to acknowledge that there's a cure in my lifetime or an effective treatment. That would be my goal.” ■

Honorary Flag Presented to Byrd Institute



Dedicated Institute supporter John Williams presents USF Health Byrd Alzheimer's Institute CEO/Executive Director Dave Morgan, PhD, with an encased American flag on behalf of Dave Harrington, a contractor working for CENTCOM Forward Headquarters at the Al Udeid Air Base in Qatar, and the 379th Expeditionary Aeromedical Evacuation Squadron. The flag was flown over Kuwait and the Al Udeid Air Base in honor of the Institute.