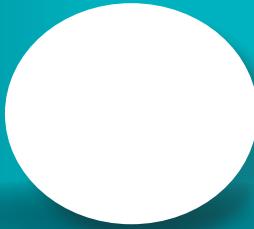




AFA Care Quarterly®

GENETIC TESTING



WHAT YOU NEED TO KNOW—
FIRST

 AFA®
ALZHEIMER'S FOUNDATION OF AMERICA

FALL
2018

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MEMBER ORGANIZATIONS DEDICATED TO IMPROVING QUALITY OF LIFE"

FEATURES



PAGE 3
Teal Take: NFL Helmet Rule



PAGE 4
**A Father and Son's Journey
with Alzheimer's Disease**



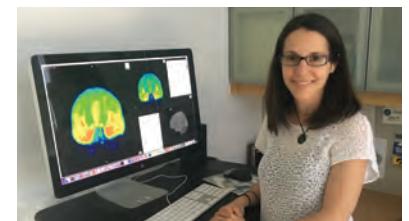
PAGE 6
Capitol Report



PAGE 8
**Genetic Testing for
Alzheimer's Risk**



PAGE 13
**Dementia Training for
First Responders**



PAGE 18
Research Update

AFA Care Quarterly®

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published quarterly by AFA.

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FALL 2018 VOL. 13 NO.4

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A MESSAGE FROM OUR PRESIDENT & CEO

Throughout my life, I've always believed that education is a tool of empowerment. Like any tool, it does not function on its own. In order to work, it needs a user who is willing and able to operate it.

One of the reasons I enjoy being part of the AFA team is that it shares that same belief; indeed, it's a cornerstone of AFA's founding principles. Everything we do strives to provide individuals with helpful information that can assist them in caring for someone with Alzheimer's disease. We also support the creation of new knowledge, whether it's through funding research or developing new training programs. The Fall 2018 issue of AFA Care Quarterly focuses on some of those efforts.

Our cover story examines the growing number of individuals using at-home genetic testing to discover their risk of developing Alzheimer's disease. AFA's Medical, Scientific and Memory Screening Advisory Board discusses some of the things that people need to consider before taking one of these tests, as well as steps that should be taken to ensure consumers are better informed and protected.

Medical correspondent and Neuroscientist Dr. Max Gomez candidly discusses his experiences with Alzheimer's, both as a son caring for his father and a journalist raising awareness about the issue. Dr. Gomez is sharing the lessons he learned along the journey in the hopes that they will help other families facing similar challenges.

We share the good news of Congress increasing federal investment for Alzheimer's disease research to \$2.34 billion in Fiscal Year 2019. For the first time, Alzheimer's research funding has now reached \$2 billion a year, the figure leading scientists say is the minimum amount needed to reach the National Plan to Address Alzheimer's Disease's goal of finding a cure or disease modifying treatment by 2025.

Read how law enforcement officers are getting new training to better protect and serve individuals living with Alzheimer's disease and other dementia-related illnesses.

Finally, learn how a team at Stony Brook University is undertaking an innovative research project aimed at improving therapies and medications to more effectively target and treat the damage Alzheimer's causes to the neurons associated with memory.

We're also excited to bring you a new section, called "The Teal Take," where AFA offers our editorial opinion on issues. Our first "Teal Take" column discusses the NFL's new "helmet rule" and why AFA believes it was a necessary step to protect players' cognitive health.

We hope you find the articles included here helpful and useful. As always, we welcome your feedback and suggestions about stories or information you would like to see in future issues. Share them with us through email at info@alzfdn.org or mail them to our office at 322 8th Avenue, 7th Floor, New York, NY 10001.

Take Good Care,



Charles J. Fuschillo, Jr.
President & CEO
Alzheimer's Foundation of America



THE TEAL TAKE



NFL Right to Develop and Enforce New "Helmet" Rule

Earlier this year, the National Football League (NFL) generated some controversy by adopting a new "helmet" rule. Under the new rule, which was developed to protect player safety, a player cannot lower his head to initiate and make contact with his helmet against an opponent. The rule is not restricted to contact of an opponent's head or neck area; initiating and making contact with the helmet against his torso, hips and lower body is also an infraction. Violations range from a 15 yard penalty to an ejection from the game, depending on the severity of the offense.

NFL Commissioner Roger Goodell poignantly stated earlier this year to the *Washington Post* that the NFL's focus is how to "take the head out of the game and make sure that we're using the helmet as protection and it's not being used as a weapon."

Critics of the new rule have voiced concerns that it is challenging to enforce and will ultimately change the character of the game. While the NFL can, and should, work to address those concerns as best it can, the new rule is a

positive step forward. The NFL's paramount responsibility is protecting players' safety. Everything else is secondary.

For years, studies have shown a relationship between sports-related injuries-and more seriously, repeated blows to the head-and Chronic Traumatic Encephalopathy (CTE). Neurologists, while acknowledging opponents' concerns that the rule may be challenging to officiate, still maintain that it's a good idea and a step in the right direction.

AFA agrees with the NFL's decision and applauds the league for taking action to protect player safety. Enforcing safety rules, however imperfect, is but a minor inconvenience to endure toward protecting one's cognitive health. We call on other sports, including at the high school level, to consider taking similar measures in the interest of safety first, as well as welcome the important insights and ongoing discoveries of researchers as they advance the science.

The health and well-being of our nation's families is paramount and should not be sacrificed for the good of any game.

A Father and Son's Journey with Alzheimer's Disease

by Linda Saslow

“If you forget where you put your keys, you're probably just forgetful,” reflects Max Gomez. “But if you forget what your keys are used for, that may be a sign of Alzheimer's disease.”

Dr. Max Gomez is no stranger to Alzheimer's. As an award-winning journalist and medical reporter for WCBS-TV, he has reported over the years about the increasing incidence of Alzheimer's, the genetics of the disease, new drugs, caregiver issues, and research on advances toward a cure. But his most open, honest and emotional reporting has been when Dr. Gomez has shared his personal experience--watching the progression of Alzheimer's disease in his father, who was one of the first Cuban-American OB/GYNs in Miami.

Having delivered more than 4,000 babies, Dr. Gomez (senior) had a successful medical practice, and was a role model and mentor to his son.

“My father was even tempered and a true fashion plate,” Max remembers fondly. “He was always meticulous about his appearance. His suits and ties were perfect, right down to the white linen pocket hanky with cologne on it.” Never would Max have believed that his dad would one day stop showering and

shaving, or that he'd forget to change his clothes for days at a time.

For Max, the original red flag arrived the day the manager of his dad's apartment complex called him to report that his father was several months behind on his condo payments. When Max couldn't reach his father by phone, he grew more concerned and immediately booked a flight to Miami. He knew that his father had been suffering from depression and hadn't been acting like his old self. But when his father answered the door, shirtless and confused, Max realized that there was something more seriously wrong than forgetfulness.

As Max paid closer attention to his dad, he discovered that his dad's personality was changing, often getting angry when told what to do. But if that wasn't enough, he learned that his father had been mismanaging his own money, allowing a “girlfriend” to write thousands of dollars of checks against his bank account. Medicare/Medicaid clinics that had used him as a figurehead medical director had been using his ID to file millions in false Medicare claims without his knowledge—eventually leading the FBI to investigate.

Over the next few years, Max became his father's caregiver,



watching him decline—slowly at first, then more rapidly until he could no longer live on his own. Max was able to convince his father to move from Miami and into an assisted living home not far from his apartment in Manhattan. While the staff there was conscientious and caring, it fell to Max to shave, bathe and get his father to change clothes because he had begun to refuse requests from the home's aides. Various health issues led to several hospitalizations until he eventually spent his final months in a nursing home. But through it all, Max recalls sadly, “My father never remembered losing his money. And he never admitted to having Alzheimer's disease.”

Max's involvement with Alzheimer's disease dates back to years before his own personal experiences, when he earned a PhD in Neuroscience based on his interest in the brain and how memories are formed and in some cases, lost. But at that time, he never envisioned leaving academia for a career in broadcasting.

That was, until as a post-doc at Rockefeller University, he attended a seminar for people interested in changing careers. “I wasn't so excited about poking rats with electrodes,” he recalls. “The seminar got me thinking about alternative career paths.”

It was the summer of 1980, when television was trying to expand its coverage to integrate health and science into its broadcasting. The timing was perfect for Max, who resigned from his fellowship and decided to give TV a try.

Max became the health and science editor for WNEW-TV in 1980 and then at KYW-TV in Philadelphia from 1984 through 1990. In 1991 he returned to New York at WNBC-TV, did a three year stint at WCBS-TV from 1994 to 1997 after which he returned to WNBC and since 2007 Max has again been the senior medical correspondent at WCBS-TV.

Over the years, Max has received numerous journalism awards—including seven New York Emmy's, two Philadelphia Emmy's, a UPI honor for Best Documentary for a report on AIDS, and an Excellence in Time of Crisis Award from New York City after September 11.

In addition, Max has received national TV journalism awards from the National Marfan Foundation and from the Leukemia and Lymphoma Society of America. He was also named the American Health Foundation's Man of the Year and was a NASA Journalist-in-Space semi-finalist in 1986.

Max has served on the national board of directors for the American Heart Association, the Princeton Alumni Weekly and the Partnership for After School Education. He also mentors undergraduate journalism and medical students, as well as physicians who are interested in medical journalism.

As a journalist with a particular interest in Alzheimer's disease, Max has reported over the past few years on exercise for Alzheimer's, Alzheimer's aroma therapy and using music to help fight dementia as well the numerous clinical trials on vaccines, drugs and other interventions trying to slow, treat or prevent the disease.

As he reflects on his own personal struggles, he admits, “People always told me that I was a great son, but it was so hard to see and watch my dad deteriorate, and I always felt guilty that I didn't do enough.”

From his experience, he is hopeful that his own lessons can be helpful to others.

“Watch for early warning signs,” he cautions. “If you see a loved one making impulsive or odd decisions, particularly financial ones, this should set off alarm bells.”

He also discourages what he calls “the martyr complex.” “It's natural to feel that you owe it to your loved ones to care for them at home all of the time,” he says. “But no one person can do what a team of caregivers can do, and it's not always a better solution to care for them at home.”

And finally, “If you have to be the primary caregiver, ask for help,” advises Max, who is an advocate, supporter and friend of the Alzheimer's Foundation of America. “There are support groups, entities like the AFA, and social groups that engage your loved one and can give you a respite from the overwhelming responsibility of Alzheimer's caregiving. Different behaviors require different types of help, but most of all, remember, that you can't do it all yourself.”



Dr. Max Gomez



CAPITOL REPORT

HITTING THE MARK

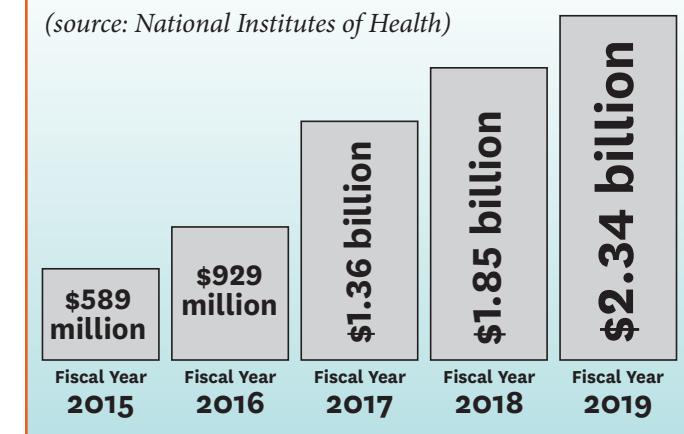
CONGRESS APPROVES HISTORIC \$2.34 BILLION FOR ALZHEIMER'S RESEARCH FUNDING

Washington isn't known for bipartisan unity, but there is at least one issue all parties agree on.

For the past several years, Republicans and Democrats have been coming together and making progress in the fight against Alzheimer's. Most recently, the House, Senate and President approved a Fiscal Year (FY) 2019 Health and Human Services budget which includes over \$2.34 billion in funding for Alzheimer's disease research at the National Institute of Aging (NIA), an increase of more than \$425 million over FY 2018 spending levels.

Federal Spending on Alzheimer's Disease Research

(source: National Institutes of Health)



Equally as important, it's the first time that federal Alzheimer's disease research funding has reached \$2 billion a year. Leading scientists said that figure is the minimum amount necessary in order to find a cure or disease modifying treatment by 2025, which is the stated goal of the National Plan to Address Alzheimer's Disease.

It's taken six years to get to that number, but after years of chronic underfunding, the progress is undeniable. When the National Plan to Address Alzheimer's Disease was unveiled in 2012, Washington was spending approximately \$500 million on

"The National Plan to Address Alzheimer's Disease calls for a cure or disease modifying treatment by 2025 and this funding gets us on a viable path toward putting this goal within the realm of possible. Maintaining the status quo when it comes to Alzheimer's is not an option."

— Charles J. Fuschillo, Jr., AFA's President & CEO.

Alzheimer's disease research. Since then, research funding has surged by more than 300 percent.

Alzheimer's is a public health crisis which demands action. Congress has not only made Alzheimer's a priority, it has delivered real results. While there is much more work to be done, the progress is encouraging. Thank you to all of our federal representatives who supported this much needed funding increase and have put us on a viable funding pathway to meet the laudable but achievable 2025 goal of the national Alzheimer's plan.

Genetic Testing for Alzheimer's Risk: What You Need to Know—FIRST

At-home genetic testing is on the rise. While genetic testing is popular to determine ancestry, consumers are increasingly utilizing it to learn their genetic risk for health factors, including the risk of developing Alzheimer's disease. But do consumers truly understand what those results will mean and the potential impacts of learning them?

AFA's Medical, Scientific and Memory Screening Advisory Board recently offered recommendations to consumers, as well as physician-scientists, policy makers and the commercial genetic testing industry, in a commentary published by the *Journal of Alzheimer's Disease*.

Step one for individuals wishing to learn their genetic risk for Alzheimer's disease through an at-home genetic test should be to consider consulting with their doctor and a genetic counselor.

"Before pursuing any kind of genetic testing, it is essential that consumers are fully informed and understand the benefits, limitations and other implications of learning one's personal health information," says Charles J. Fuschillo, Jr., AFA's President and CEO. "This includes having insight on how a test result might impact the individual and their family emotionally, particularly in the case of Alzheimer's in the absence of a cure, or an effective treatment."

Since the April 2017 FDA approval of direct-to-consumer testing for genetic disease risks, including APOE—apolipoprotein-E, a "susceptibility" gene for late-onset Alzheimer's disease—the number of consumers accessing their genetic information has exploded. And with effective and sustained marketing campaigns by commercial testing entities, the sales of the tests (and presumed use) have already skyrocketed^{[1][2]}. But without proper counseling and

education, consumers may be misinterpreting the results.

"To begin with, people may wrongly confuse genetic risk with genetic certainty—or a diagnosis; the distinction between risk and causation must be made clear to consumers. APOE genes affect the probability of developing Alzheimer's, but APOE does not by itself cause the disease," cautions J. Wesson Ashford, MD, PhD, Chairman of AFA's Medical, Scientific and Memory Screening Advisory Board. "It is important to understand that many individuals who have the APOE susceptibility gene never get Alzheimer's. At the same time, not having an APOE susceptibility gene doesn't mean that person will never develop Alzheimer's in their lifetime."

Consumers and policymakers also must be concerned that genetic information could be used to negatively impact individuals when trying to

purchase certain insurance products.

"While the current Genetic Information Nondiscrimination Act (GINA) offers some protections^[3], in a few states, long-term care insurance and life insurance companies still have the right to ask if an individual knows their genetic status and adjust long-term care insurance premiums accordingly," says Fuschillo. "Therefore, the ways in which personal health information—including genetic status—could be used has important implications, posing risks to consumers over which they may have little control."

Consumers should also remain vigilant about the risks of unintended disclosure of genetic testing information through computer hacking or other data security breaches. "As with an individual's social security number, their genetic information needs to be safeguarded from those seeking the information

for exploitative or criminal purposes," Fuschillo added.

On the positive side, research has shown^[4] that individuals who undergo testing and become aware of their own genotype may take pro-active steps to plan for and optimize their future lives, e.g., make lifestyle changes and actually benefit from early detection.

"It's worth noting that those with normal cognition and a genetic predisposition for Alzheimer's may elect to enroll in clinical trials aimed at delaying the onset of Alzheimer's-related symptoms, or preventing it altogether at some point," says Lori Frank, PhD, a member of AFA's Medical, Scientific and Memory Screening Advisory Board.

Some guidance to the lay public is provided by commercial genetic testing firms, but currently there are no industry-wide standards on these consumer guidelines.

Recognizing the level of public interest in genetic testing for late-onset Alzheimer's disease, AFA and its advisory board are recommending that testing companies adopt standardized consumer guidelines and that easy access and/or referrals to appropriate information and resources—including to qualified genetic counseling professionals—is provided as part of the testing process.

Some suggest that the physician's office is the only appropriate venue for learning these results, but others disagree. "While physicians certainly could provide appropriate guidance about risk and offer insights into treatment options, the reality is that most clinicians lack the training and report feeling ill equipped to address genetic test results. In our view, given the rapidly growing use of genetic testing, training in interpreting and explaining the genetic test results should be included in the education of health professionals. This training can address when referral to genetic counseling is appropriate," says Frank.

AFA and its advisory board are also calling on researchers to revisit past analysis of Alzheimer's disease genetic disclosure and conduct new research on how such information can influence both negative and positive outcomes, including lifestyle modifications, as well as future planning.

"We recognize the growing importance of genetics in Alzheimer's disease diagnosis, as well as the emergence of personalized medicine, which we hope will one day lead to more effectively targeted individualized therapies. However, we have to do this right and with the best interests of consumers in mind," says Fuschillo.

photo credit: © Sergunt | Dreamstime.com



MORE ON THE GENETICS

While APOE is frequently referred to as a susceptibility gene only informing on the risk of developing late-onset Alzheimer's, there are three known "deterministic" (causative) genes for young-onset Alzheimer's, which are quite rare: specific mutations in the amyloid precursor protein (APP), and the presenilin proteins (PSEN 1 and PSEN2)^[5].

These mutations are considered "deterministic" because they cause Alzheimer's disease at a relatively younger age, well before an individual is more likely to die from some another cause.

Nearly all individuals who have one of these mutations in APP or PSEN1 will develop Alzheimer's at a young age. In contrast, mutations in PSEN2 show 95% penetrance, meaning that not everyone with a PSEN2 mutation will get Alzheimer's^[5].

Among the young-onset genetic factors, which include several unknown genes as well, the impairment of memory and other cognitive functions begins before 60 to 65 years of age and accounts for 1 to 5 % of all cases.



photo credit: © Esra Keskin Senay | Dreamstime.com

By contrast, late-onset Alzheimer's disease, occurs after age 60 to 65 and is the predominant form of Alzheimer's disease^[5]. Late-onset Alzheimer's disease is frequently associated with the APOE-epsilon-4 gene. It occurs about 12% of the time in approximately 22% of the Caucasian population, and is found in about 60% of persons with Alzheimer's. The APOE-epsilon-3 gene is the most common form of the gene; individuals with only this gene represent approximately 60% of the U.S. population, but only 35% of the cases. The APOE-epsilon-2 gene occurs about 6% of the time and appears to protect against Alzheimer's disease. Other protective genes against Alzheimer's disease have also been identified.

To date, only health care provider testing is available to identify the rare mutations (APP, PSEN 1 and PSEN2).

Currently, Alzheimer's disease is the sixth leading cause of death in the United States^[6], yet it is the only disease state in the top 10 causes of death for which there is neither a cure nor impactful treatment.

A full copy of a formal statement by AFA and its advisory board, which was referenced in the commentary, can be found at www.alzfdn.org/genetesting.

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RECIPE FOR YOUR HEALTH



SIMPLY SEARED SCALLOPS

Seafood is a protein source with benefits

A good rule of thumb is "heart healthy" is also "brain healthy." For the general population, consumption of about 8 ounces per week of a variety of seafood, which provide an average of 250 mg per day of EPA and DHA (omega 3 fatty acids), is associated with reduced cardiac deaths among individuals with and without preexisting cardiovascular disease.

DID YOU KNOW THAT SCALLOPS ARE MORE THAN 80 PERCENT PROTEIN?

- One serving is 3.5 ounces (100 grams) per person, which equals 4 to 5 large scallops, 9 to 12 medium scallops or 15 -20 small scallops.
- 3 ounces of scallops contain 90 calories, 17 grams of protein and 25 percent of the daily value for selenium.
- Scallops are low in fat.
- Both wild and farmed scallops are available.
- Avoid scallops packed in water with preservatives. Instead ask for "dry scallops."
- In addition to vitamin B12, scallops are a good source of magnesium and potassium.



Recipe and photo by Layne Lieberman, MS, RD, CDN, culinary nutritionist and award-winning author of *"Beyond the Mediterranean Diet: European Secrets of the Super-Healthy."* For more information and recipes, visit www.WorldRD.com

SIMPLY SEARED SCALLOPS (SERVES 4)

- 1-tablespoon cold-pressed extra-virgin olive oil
- Freshly ground black pepper to taste
- Sea salt to taste (optional)
- 1-pound "dry" sea scallops

Purchase fresh, dry-packed scallops (not the "wet-packed" kind) and place them on a large plate. Pat them dry with a paper towel. Season both sides with freshly ground black pepper and a small amount of sea salt. If you're following a low-sodium diet, avoid the salt. Heat a skillet on medium high and add one tablespoon of olive oil. Lay the scallops in the skillet (do not over crowd the skillet).

Sear the scallops on one side for about 2 minutes, until the bottoms are caramelized. Turn them and sear on the other side for 1 to 2 minutes, depending on size and thickness.

Serve with mango chutney, steamed green veggies and your favorite whole grain.

Nutrition facts per serving: 130 calories, 19 grams protein, 183 mg sodium (no salt added) 365 mg potassium, 2.7 grams carbohydrates, 4.4 grams fat.



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At Merck, we are inventing for life. So when it comes to diseases like Alzheimer's, which can cast a shadow over a person's sense of hope, optimism, and even their identity, we're committed to the fight.

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FEATURE STORY



Adding Teal to the “Thin Blue Line” Dementia Training for First Responders

On a daily basis, first responders answer the call to provide help to those in need. But what if that person has dementia?

More than 5 million Americans are living with Alzheimer's disease and that figure is projected to rise. Continued growth in the number of individuals affected by Alzheimer's disease increases the likelihood that an officer will encounter someone with a cognitive impairment in need of assistance at some point in their career.

Recognizing that it's not just healthcare professionals who interact with individuals living with Alzheimer's disease, AFA has provided training programs for public safety agencies such as the Transportation Security Administration (TSA), which provides security at all of America's airports, and the Port Authority of New York and New Jersey Police Department, which safeguards travelers at major New York-area transit terminals. Recently, it

expanded those efforts further, hosting an educational and training conference specifically for first responders.

Working together with Project Lifesaver International, a non-profit, community-based, public safety organization and longtime AFA member, AFA held a day long training program in Fairfax, Virginia for law enforcement. Over 100 police officers from Virginia, West Virginia, North Carolina, Maryland, Pennsylvania and Ohio took part in the event.

The physical and cognitive challenges Alzheimer's causes to the

“Law enforcement continually practices and trains how to respond to different situations they may encounter in the course of their duties. That way, they are ready to handle them safely and effectively. We want to help them be as prepared as possible to help someone who has Alzheimer's.”

—Chief Gene Saunders, Founder and CEO, Project Lifesaver International.

person living with it can also hinder a first responder's ability to do their job. Individuals with Alzheimer's disease or other dementia-related illnesses can have trouble communicating effectively, answering questions or remembering how, or who, to call for help. Memory loss may even prevent them from responding to their own name. Recognizing a situation where a person's behavior may be caused by a cognitive impairment, as opposed to willful defiance, is an important tool for first responders to have.

Officers learned the basics about Alzheimer's disease and dementia-related illnesses, along with the differences between these conditions,

mild cognitive impairment and normal age related changes to memory. Participants received instruction about the signs of

cognitive impairment, so that they can more ably spot someone in need of assistance. The importance of positive communication was also stressed; speaking in a calm, clear and friendly tone, with good body language, is critically important to keeping the individual relaxed and calm.

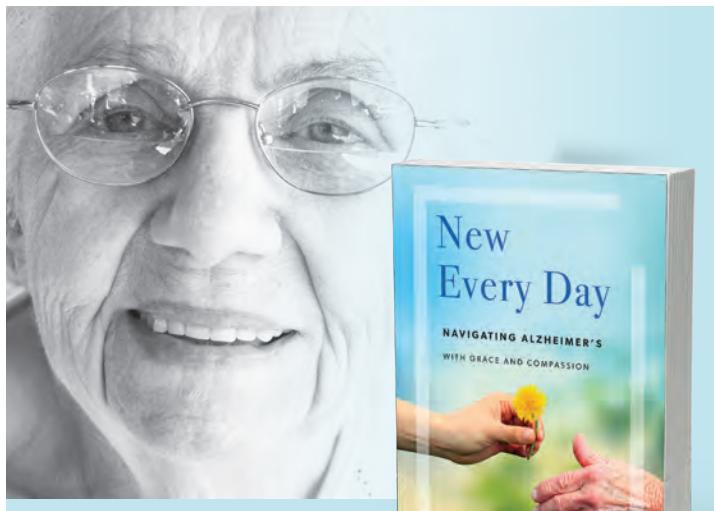
Officers also learned about the different search and rescue techniques, along with advances in technology, which can aid in the safe return of someone who wanders away from safety. Wandering is a very common and dangerous behavior among individuals with Alzheimer's disease. Project Lifesaver has been a pioneer in developing and utilizing locating techniques and technology specifically for individuals with cognitive impairments. These techniques have helped law enforcement agencies reduce search and rescue times from hours, potentially days, down to minutes.

Using the knowledge they gained, officers will be able to put their enhanced skills to use in their communities and share the lessons they learned with their fellow officers.

"Seeing so many officers participate in this program, eager to learn and thankful for the knowledge, was really special. Protecting and serving others is a passion for them; they are ready and willing to answer the call for help whenever it comes. This new training will help them make an even greater difference for families affected by Alzheimer's in their time of need," added Charles J. Fuschillo, Jr., AFA's President and CEO.



AFA staff educating Port Authority of New York and New Jersey Police Department cadets about Alzheimer's disease.



A friend

on the journey of caring for your loved one with Alzheimer's. Practical information and true stories from Dave Meurer's own experiences navigating life with a loved one who suffers from Alzheimer's. **New Every Day**, offers hard-earned wisdom and some badly needed comic relief for those journeying down this difficult road.

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Charity Gift Cards: A New Way to Give the Gift of Giving this Holiday Season



Charity Gift Card



Charity Gift Card



Charity Gift Card



Charity Gift Card



Charity Gift Card



Charity Gift Card

TisBest allows people or businesses to buy gift cards to give to as gifts. The cards work just like other gift cards, with one important exception; instead of spending the gift card at stores to buy merchandise, recipients use the gift cards to make charitable donations through TisBest's website to the charity of the choice. AFA is a participating TisBest charity.

"I love to hear how businesses are giving TisBest charity gift cards instead of gift baskets and parents are tucking TisBest charity gift cards into children's stockings, along with toys, to introduce the kids to the joy of sharing with others," adds Marks in his message.

TisBest is making a difference; TisBest gift cards have generated more than \$40,000 in donations to AFA since AFA became a participating charity!

You can purchase TisBest gift cards by visiting www.tisbest.org. Be sure to tell the recipient that AFA is a participating charity!

How it works:

- Purchase a charity gift card and customize the appearance of the card and amount of your gift.
- Give the charity gift card to the recipient as you would any other gift.
- The recipient donates the card value to the charity of their choice (AFA is a participating charity).

Giving a gift is one of the most thoughtful ways to show affection or appreciation. Finding that gift, however, can sometimes be challenging; what do you get someone who doesn't need anymore "stuff"?

TisBest Philanthropy seeks to provide that answer with charity gift cards!

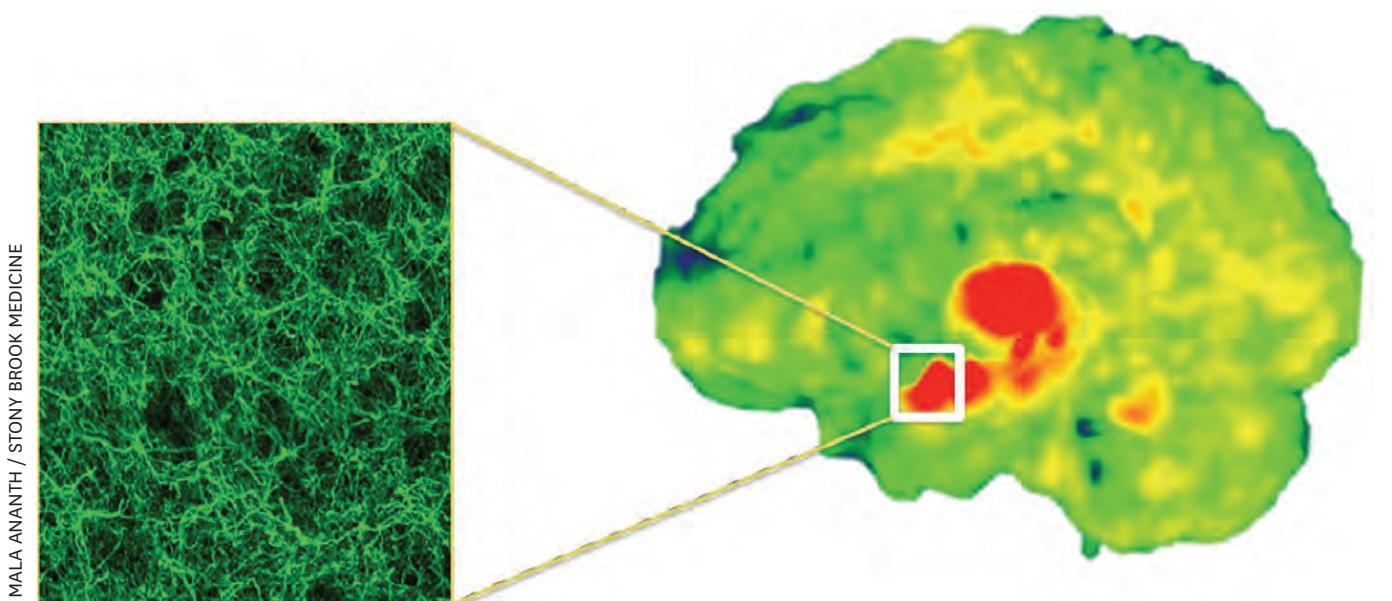
TisBest Philanthropy is a 501(c)3 nonprofit organization founded by Erik Marks with the goal of creating a donation gift that would be widely recognized and appreciated.

"The media tries to tell us that you can say 'I care more' by buying a more elaborate or more expensive gift. Although an expensive item purchased from a fancy store might make a great gift for some people, I have a different idea about what makes a wonderful gift. I believe there is too much focus on gifts of 'stuff' and that a donation gift is often the most appreciated and satisfying gift of all," writes Marks in his Founder's message on TisBest's website.

Using ADVANCED BRAIN IMAGING in Health and Alzheimer's to IMPROVE DRUG DEVELOPMENT

The most commonly used medications to improve memory in neurodegenerative diseases target a set of neurons critical for memory called cholinergic neurons. But the drugs, known as cholinesterase inhibitors, are not very effective. In an effort to develop treatments that more specifically target the damage, Christine DeLorenzo, PhD, and her colleagues—from the Departments of

Neurobiology and Behavior of Stony Brook University and Pharmacological Sciences, Psychiatry and the Center of Excellence for Alzheimer's Disease of Stony Brook Medicine in New York—are comparing the cholinergic system in healthy brains with those in Alzheimer's disease to determine what goes wrong in Alzheimer's disease. AFA provided over \$206,000 in grant funding to support the research.



Mapping the Cholinergic System: Positron Emission Tomography (PET) image of a healthy human brain. (A cross section is shown, in which the left to right direction would be from the eyes to the back of the head.) The dark yellow and red colors indicate areas of high density of cholinergic neurons. Each person receiving PET imaging also performs memory assessments, to relate cholinergic density to memory ability. (Left) To examine the cholinergic system in higher resolution than possible in a living human brain, we also perform microscopy and PET imaging in rodents. These rodents are genetically manipulated so that the cholinergic neurons and all axons and dendrites from them appear green, allowing them to be carefully assessed and counted. The inset shows the complexity and density of these cholinergic axons (green lines) in a region with high cholinergic density. These high-resolution rodent images improve our understanding and interpretation of the human imaging.

Dr. DeLorenzo is Associate Professor of Psychiatry and Biomedical Engineering and Electrical and Computer Engineering. Her co-investigators include: Ramin Parsey, MD, PhD; Lorna Role, PhD; David Talmage, PhD; Nikhil Palekar, MD; and Mala Ananth.

"We believe that we may be able to improve the efficacy of current treatments by gaining a better understanding of the structure and function of cholinergic neurons in healthy controls and comparing how these neurons are damaged in Alzheimer's," says DeLorenzo.

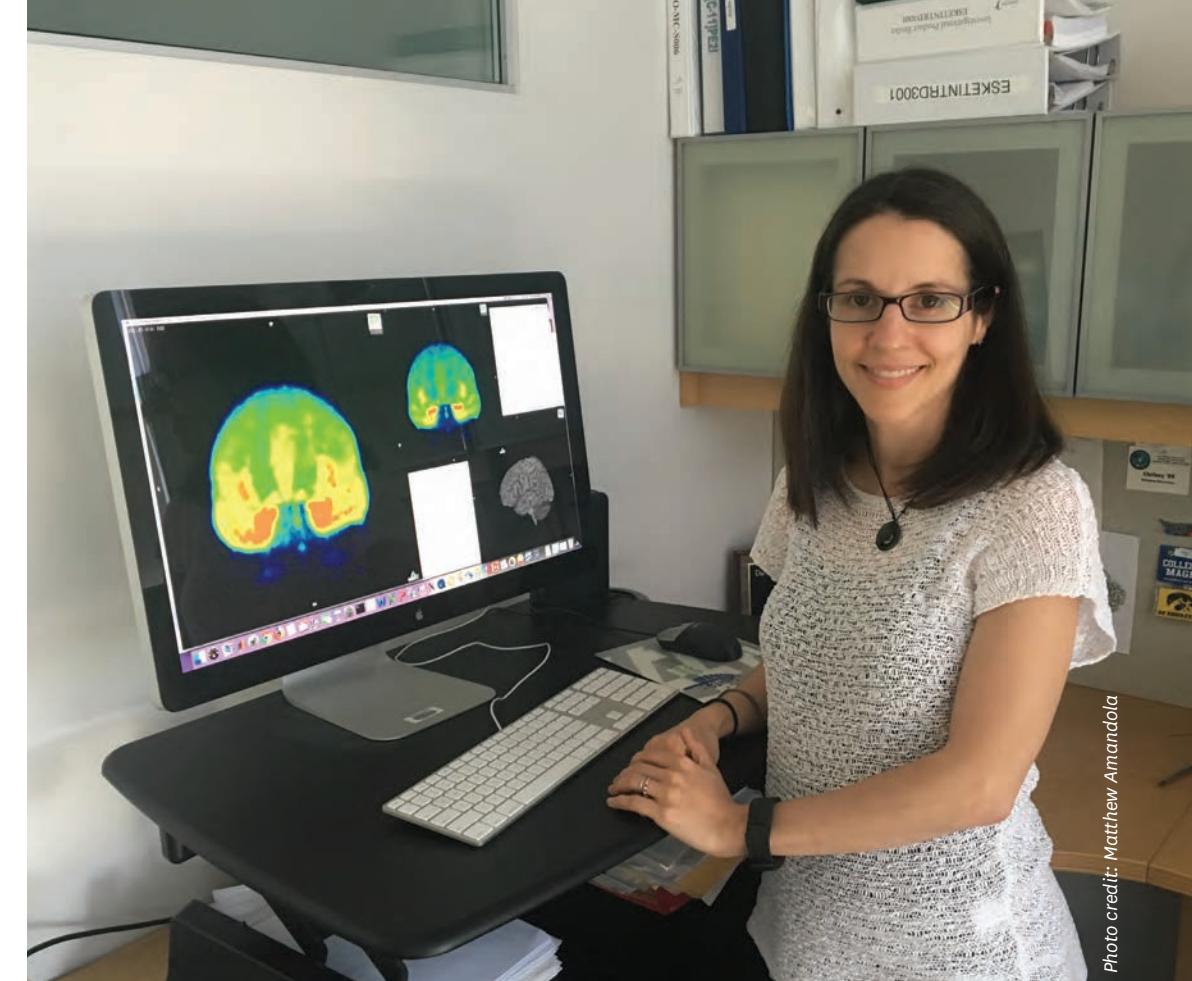
In the study, the investigators will use a translational approach—a parallel analysis in rodents and humans—to reveal such clues. To understand how disease-induced changes in the cholinergic system are related to memory, the investigators need to see the effects of these changes in both humans and mice.

First, using high-resolution microscopy, genetic techniques, and PET imaging, the researchers will visualize and quantify the cholinergic system in healthy mice and in a mouse model of AD. Parallel assessments using PET and MRI will be done in the humans. Memory assessments in the mouse models will then be compared to data generated from memory assessments of the human participants—again involving both healthy controls and those with Alzheimer's disease.

It has been known for decades that the loss of cholinergic

function is a hallmark of cognitive decline. Yet, says the researchers, medications that target the cholinergic system—the most widely used treatments to improve memory—have only a modest effect.

"Determining why this is has been a challenge in the field," says DeLorenzo. "The answer likely lies in our need for a more precise understanding of the cholinergic system in health to identify what is broken in Alzheimer's. Such insight may lead to improved therapeutic strategies that are more personalized to the individual."



Christine DeLorenzo, PhD

Photo credit: Matthew Amandola





Kara Rogers, LMSW, answers your questions

Question 1

My husband's doctor said being more active can help with his Alzheimer's symptoms. What types of activities should I be doing with him, especially since we have financial and transportation restrictions?

Care partners often have many things they are tasked with managing for the person they are caring for, from food, to medication, personal care, medical appointments and finances just to name a few. With all of these balls in the air, care partners can also play a big role in ensuring their person has meaningful activities to engage in to assist in maintaining quality of life. This can feel overwhelming.

Keeping active as we age is good for our overall health and wellness. This remains true for individuals living with Alzheimer's disease; participating in something that interests them at whatever capacity they can, where it encourages them not discourages.

Your person is the expert of their own life. Ask what they would like to engage in. If they cannot verbalize, go back to their hobbies, or try a variety of different activities and see what the response is. Figuring out what activities will work best for them will also be a trial and error process. As they progress with the disease their interests can change, and we need to remain adaptable. It just means we need to assist in helping uncover something new that will excite them.

Suggest different things they can do. Two options, given the opportunity for choice, are recommended, as many different options can be overwhelming. As you discover together what their dislikes are, you can cross them off the list.

Use that home-field advantage to look around your home to see what is around you that could inspire an activity. As it can

be costly, we want to see if there are items, games or other objects you could create or modify into something really wonderful. Your person can create something out of items from around the home. Creating stations around the home for engagement and entertainment can also be helpful – comprised of their interests and things they like. Make sure the activities that you choose from are not too complicated so not to discourage, but also age appropriate for the older adult and not something intended for children.

The internet has unlimited resources of ways to personalize activities and entertainment for your loved one. For example, YouTube is a great website that can show different exercise classes or gentle movements with people doing things like chair yoga or some dancing that could be a way for the person to be active. Of course this is a way for the person to participate at whatever capacity they can. The goal is for the person to move more at their own rate because again we don't want them to be discouraged.

If transportation is an issue, reach out to organizations such as your local area agency on aging and see if they have transportation services to escort your person to and from programs. See if your community has a friendly visiting program, which provides a social opportunity for individuals with Alzheimer's to interact with another person in a one on one setting.

Taking all of this on can be stressful, but remember the goal is for your loved one to live the best life possible for as long as they can.

Question 2

My mother is having a hard time going to sleep as she is worried that someone is coming to evict her out of the house. What can I do to comfort her?

Hallucinations and delusions are symptoms of Alzheimer's, especially in the middle stages of the illness. Hallucinations can be things that they hear or see that are not there. For example, they could be seeing animals in their room or hear voices talking to them. Delusions are fixed, false beliefs such as the belief that someone is breaking into the home and stealing their things, or in this case with your mother, that someone is going to evict her from her home. First and foremost, protect mom's safety and speak with a medical professional to ensure there is no underlying medical reason that could be causing these delusions.

When your mother is expressing her beliefs, focus on easing her anxiety and assisting her in feeling safe and secure. Often, despite our best intention, correcting her may make her more upset. Let her know that you are there to listen to what might be upsetting her. Asking questions about what she sees, hears or thinks may help you to better

understand what is concerning her and assist in reducing her fear of eviction.

If the person is experiencing something that is positive and non-intrusive, such as seeing their dog from childhood, join them in this discussion. Engage the person and learn as much as you can from them about the dog. This redirection can assist connecting you to their world as well as continue to keep the person in a positive and calm space.

A few other good rules of thumb to best assist when situations like this arise:

- Using soothing tone of voice and gentle touch if the person is willing. This can help to reassure and reduce stress and anxiety.
- Know what they like. What would help to reduce their anxiety? Music, aroma therapy, a cup of tea, companionship, a soft blanket or a pet are all great options depending on the person's preference.
- Be mindful of your body language when engaging with the person.

Each person is different and what soothes them can change as they progress through the disease. Learn about your person and see what works for them.



Contact our social workers seven days a week through AFA's National Toll-Free Helpline at 866-232-8484 or through our website, www.alzfdn.org.

MAKING A DIFFERENCE



The Respite Care Relief Park, which AFA and the Town of Babylon opened in November of 2017, is normally a quiet place. On one October Saturday morning, it was filled with hundreds of enthusiastic people eager to make a difference in the fight against Alzheimer's disease.

The occasion was the Alzheimer's Walk in the Park, sponsored by AFA and the Town of Babylon. Walkers from across Long Island braved the rain and

came together to raise Alzheimer's awareness and funds to support families affected by Alzheimer's disease.

A sea of teal flooded the park, which is a dementia-friendly place where caregivers can go to get out of the house, enjoy the outdoors and feel comfortable bringing someone with Alzheimer's disease.

Walkers did laps around the park's lake, often dedicating their

walk to a loved one with Alzheimer's. Students from local high schools not only walked but served as volunteers at the walk. One area business sent a team of employees to take part.

Local small businesses supported the event, donating funds, refreshments, services and entertainment. Free memory screenings were provided at the event.

"What better place to raise Alzheimer's awareness than at a park built specifically to help individuals with Alzheimer's disease," said Charles J. Fuschillo, Jr., AFA's President & CEO. "Seeing the community embrace and support the walk was really something special."

AFA plans on building other Respite Care Relief Parks and holding additional Alzheimer's walks across the country. Contact AFA at 866-232-8484 if you're interested in building a park or hosting a walk in your community.

Alzheimer's Walk In The Park





ALZHEIMER'S FOUNDATION OF AMERICA

322 Eighth Avenue • 7th Floor
New York, NY 10001

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