

TEAL TIMES

A Publication of the Alzheimer's Foundation of America

Vol. 8, No. 2



Alzheimer's
Walk 2023:
One Weekend,
One Cause

A MESSAGE OF THANKS FROM OUR PRESIDENT & CEO **CHARLES J. FUSCHILLO, JR.**



Our annual Alzheimer's Walk in the Park weekend is one of our favorite fundraising events of the year, with individuals and teams coming together for a day of hope, inspiration and fun. This year we raised \$124,000 and lots of smiles. We hope that you'll join us in September 2024—we are shoring up the dates now.

Fundraising for AFA doesn't end with the Walk though. Passionate AFA friends inspire us all year long.

- Dustin Gunderson is swimming the seven Finger Lakes in New York in honor of his dad. "A little impulsive and spontaneous, for sure," he admits. But we are impressed and inspired by his gesture and dedication.
- The Sisters of the Congregation of St. Joseph spent their working lives educating others. For a week in June, they educated themselves about Alzheimer's, wanting to be in solidarity with the members of their community who are living with dementia. They created a spirited fundraising event, too, that raised over \$700.
- Jake's 58 Casino Hotel customers "donated their change" to AFA, raising \$19,000.

When we combine our efforts, we do amazing things.

If you are interested in creating your own fundraiser to support our programs and services, call David Leon, AFA's fundraising specialist, at 866-232-8484, or go to our website, alzfdn.org, click on the "Donate" tab and then "Create Your Own Fundraiser."

This issue of *Teal Times* also highlights some of our recent Alzheimer's research initiatives. Our board of directors approved funding for Emory University, One Mind and the Hadassah Medical Organization.

We are proud to share our continuing educational outreach effort with the publishing of AFA's new children's book, *Gardening with Grandma*, and to recognize our AFA's Teen Alzheimer's Scholarship '23 winners.

And this year, our Light the World in Teal annual awareness campaign reached more than 1,000 landmarks in all 50 states and 13 foreign countries.

We are inspired by and grateful for all of you.

May 2024 bring you good health and happiness,

Chuck

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Swimming the Finger Lakes for AFA



In a gesture that was “a little impulsive and spontaneous, for sure,” Dustin Gunderson, 46, responded to the March diagnosis that his father had

dementia by deciding to swim all seven of the Finger Lakes as a fundraiser for AFA.

“I wanted a challenge and a way to raise money for a cause that is near and dear to my heart.”

In researching for a nonprofit to benefit from his fundraiser, he was impressed with the information on AFA’s website about the various forms of dementia. “For a long time, I didn’t understand the difference between Alzheimer’s and other dementias. I had a conversation with my father’s doctors and realized he had a form of vascular dementia resulting from a series of strokes.”

His father, Tom, who is doing well, was “a little apprehensive” when he learned his son wanted to set up a fundraiser on AFA’s website.

“My parents are more private. They’re not used to social media. I talked to him and my mother and told them there’s no reason to be ashamed. It’s just another disease and that maybe by telling their story it can have an impact on others in similar situations.”

Dustin started his swimming challenge in early July at Owasco Lake on the edge of Auburn, NY, after reaching out to some 40 people to ask for their financial support. By the end of the summer, he had checked off five of the seven Finger Lakes and raised close to \$6,000 toward his goal of \$10,000.

When he starts up again next year, he intends to approach local business in Skaneateles, where he lives, and thinks their contributions will set him over his goal. He swam Skaneateles Lake on July 31.

He doesn’t ask for pledges for miles, rather he asks people to contribute to his page on AFA’s website – <https://apps.alzfdn.org/afafundraising>

He swims alone but always has at least one friend in a boat beside him for conversation and to deter other boats from coming within 50 feet of him. His longest swim was close to two hours.

A former college athlete and current triathlete, he trains in the winter in the pool at the local YMCA, building his swimming around his life as a father of two and his 20-year career as a law enforcement officer with the National Parks Service. He now works at the Delaware Water Gap National Recreation Area in northeast Pennsylvania/northwest New Jersey.

“I encourage people to choose something challenging and go for it.”

AFA is immensely grateful that Dustin went for it.

Photos courtesy of Dustin Gunderson



AFA Invests \$400,000 in Alzheimer's Research

AFA has awarded \$400,000 in grant money over the past year to increase support for people in African and Black American communities, back visionary founders of early-stage startups that take innovations to market faster, and to support research aimed

at developing inexpensive medications that maximize accessibility to more people. The grants were awarded to Emory University's Goizueta Alzheimer's Disease Research Center, One Mind and the Hadassah Medical Organization.



Emory University's Goizueta Alzheimer's Disease Research Center

A grant of \$200,000 was awarded over a three-year period to fund outreach and educational programs for African American men and to increase their participation in research. Powerful cultural, economic and historical factors hinder African Americans' engagement in medical research, producing stark racial imbalances in understanding the clinical, pathological and genetic features of disease. Alzheimer's disease occurs in all types of people but is twice as frequent in African and Black Americans, who are often diagnosed at later stages.

Studies suggest that these disparities may be related to a higher incidence of hypertension, genetic influences and environmental exposures.

The Center is tackling these problems by recruiting African American research participants and training talented African American investigators. The training programs are creating a pipeline of scholars to help develop research breakthroughs, interventions and treatments for African Americans living with Alzheimer's disease.



One Mind

A grant of \$100,000 was awarded to support the One Mind Accelerator, which backs visionary founders of early-stage startups with the catalytic tools – network, education and capital – to rapidly build robust, scalable and ethical companies that take innovations to market faster and with greater impact for people facing serious mental illness. One Mind projects this program will enable 15,000 to 45,000 people to receive cutting edge treatments and services over the next five years.

Since 1995, One Mind has become one of the leading brain health nonprofits in the United States committed to catalyzing visionary change through science, business and media to transform the world's mental health. It works to heal the lives of people impacted by brain illnesses and injury through global, collaborative action.



The Hadassah Medical Organization

A grant of \$100,000 was awarded to support research aimed at developing inexpensive medications that maximize accessibility, through cost and tolerability, to a global and inclusive patient population from a variety of socioeconomic backgrounds and healthcare systems. Scientists and physicians in the Department of Neurology are engaged in clinical treatment and research into neurological diseases – the causes, advanced treatment options, preventive measures and potential cures.

The Hadassah Medical Organization occupies a preeminent position in Israel as a national referral center for the most complex and challenging medical conditions, especially in the field of neurology.

Making Memories Fall Social Raises \$65,000



Honorees Julia Bodner Cohen and Brett Cohen, center, with family and friends.

AFA's volunteer Professional Leadership Council (PLC) held its first Making Memories Fall Social in October to a packed house at The Blond at 11 Howard in New York City.

Founding member Brett Cohen and wife, Julia Bodner Cohen, were the evening's honorees for their commitment to helping families impacted by Alzheimer's. It was their personal experience with Julia's grandfather Marty who is living with Alzheimer's that brought the couple to the Council.

Julia shared that watching her dad and his siblings make decisions regarding her Papa were emotionally challenging, but the hardest was watching "the gregarious, dog loving, magic performing, French toast chef extraordinaire" become "the shell of the person he once was." Seeing how this experience impacted Julia's family, Brett was inspired to join the PLC. The couple now make the cause a priority in their lives, using their resources and network to draw attention to the needs.

"This is a very special night for us," Matt Solomon, chair and founding member, remarked. "We are supporting a great cause and honoring great people."

More than 150 guests attended the sold-out Making Memories event and raised \$65,000. AFA's Professional Leadership Council was founded to empower a new generation of AFA advisors and ambassadors.

MUCH GRATITUDE TO THE AFA PROFESSIONAL LEADERSHIP COUNCIL COMMITTEE

*Matt Solomon (Chair),
Brett Cohen (Founding Member),
Daniel Fuschillo (Founding Member),
Danielle Wattenberg (Founding
Member), Jeff Bergman,
Julia Bodner Cohen, Julie Giacinto,
Errol Jones, Matthew Knee,
Lane Manning, Eric Mayer,
Siobhan Miller, Howard Nevins,
Josh Rieders, Noah Shulman*



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Hair Salon Raises \$1,000 for Charity Close to Heart



“Every single person who donated said it was because they were personally touched by Alzheimer’s and dementia,” Rush said. “It’s kind of crazy that the first charity that we pulled out of the hat was Alzheimer’s. This disease touches way too many lives.”

When Regina Rush bought Bella Salon in July 2022, she brought with her years of experience in the beauty industry. She also brought a caring heart. As it turned out, New Jersey’s Manchester Township was a great place for her to express these two elements of her life.

“My mission statement and vision include charity as a pillar of our purpose,” she says. “We agreed that we would hold two fundraising events a year. All of my employees put a cause that is close to their heart on a post-it note, and we keep them in a bag to draw. The first one we drew was Alzheimer’s.”

It’s hard to imagine how that random drawing could have benefited a better cause for Bella’s customers.

“It was actually quite fitting for our community. We live in a retirement area with a generation that is aging into their 80s and 90s,” Rush says. “Alzheimer’s and dementia have hit our community hard and are devastating to my customers. More and more often, we lose customers that have been coming to us for 18 years, before I bought the business. They’re going to nursing homes because their families can no longer care for them.”

Many patrons also come with their home aids, “and we can see the toll this disease takes on them over a long or even short period of time.”

After Alzheimer’s was pulled out of the hat as the first charity, Rush researched organizations she thought would best represent the cause and found AFA, which she deemed “one of the most highly rated and reputable.”

A “tricky-tray” table was set up in the salon for a week in May with gifts donated by local merchants, including two pairs of Air Pods Pro 2nd Gen and gift certificates for nearly a dozen local businesses. People purchased tickets for the prizes they wanted, with all the proceeds going to AFA. In addition, the salon held a cut-a-thon for which some staff members donated their time on a Saturday to do haircuts and spa pedicures. Half of the service proceeds went to AFA.

The salon met its goal of \$1,000, surpassing it by \$122.

St. Joseph's Convent More Than Helping Out

The Sisters of the Congregation of St. Joseph spent their working lives educating others. For a week in June, they decided to educate themselves. The topic: Alzheimer's. They wanted to be in understanding and solidarity with the members of their community who were living with this disease and other dementia illnesses.

Every day on their lunch tables at the convent, in Brentwood on New York's Long Island, they found information about Alzheimer's, such as how to distinguish normal aging from aging with a form of dementia. The week culminated in the congregation's first fundraiser, a raffle for AFA, which raised \$722.



Recreation director Kerri Guarascio said they chose AFA because unlike other organizations they researched, "we knew the money would go directly to Alzheimer's research and funding."

For the June 6 fundraiser the four members of the recreation department made a collection of items to be raffled that included handmade crocheted elephants, blankets, terrariums and prayer shawls.

"We all used our own talents to come up with different items for the raffle table," Guarascio said. Tickets were six for \$5 and "many sisters gave generous donations."

The items were displayed in the main dining area for a few days, so everyone had a chance to get involved.

On the day of the event, staff and sisters participated



in an outdoor Olympics that included noodle javelin throwing, bean bag toss and ice cream.

All but one of the 58 sisters are retired. Most had been teachers, some were nurses, one was a doctor and one a lawyer. "We were involved in almost everything," said Sr. Carmelina Lally, CSJ, who worked in daycare programs in Huntington and Farmingdale.

Many of the sisters volunteer now in the different nonprofits that operate independently on their 212-acre property, most dealing with issues of justice and immigration. Forty recently arrived immigrants, mostly from Afghanistan, are housed in one of the facilities. The property also features what is possibly the largest installation of solar panels on Long Island, reflecting the sisters' concerns for land ethics and the environment. For Sr. Carmelina and the other sisters, becoming involved is natural.

"They come prepared to help out because that's the kind of people we are here."



Photos courtesy of the Sisters of the Congregation of St. Joseph



One Weekend, One Cause:

The weather of the two days could not have been more different in New York: sunshine and humidity followed by torrential rain. But the enthusiasm for the cause, hundreds of people walking in honor of their loved ones for the AFA mission, was in full force the entire Alzheimer's Walk in the Park September 9-10 weekend. Teams on Long Island, in New York City and virtually across the country raised \$124,000 to help families impacted by Alzheimer's.

The Long Island Alzheimer's Walk, on September 9, took place at Eisenhower Park, site of AFA's new Respite Care Relief Park.

The team for Gurwin Healthcare System, our 2023 Walk chair, enthusiastically represented with more than 40 walkers participating.





We Walked

In New York City, on September 10, Walk participants ended up huddled under tents on Manhattan's Battery Park Esplanade, to manage the torrential rains that came.

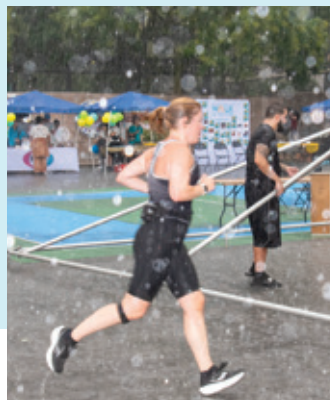
Charles J. Fuschillo, Jr., AFA president and CEO, reminded everyone, "This is nothing compared to what individuals and families have to endure living with Alzheimer's."

Many participants, despite the rain, felt energized for the work that continues for our community.



Said Janet Pescatore, walker and AFA volunteer, "What sets AFA apart for me is that they help the caregivers along with the patients, and that's very important to me. Please keep fundraising because the work is ongoing."

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Cabaret Performance in AFA's Honor



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Jarrett Winters Morley holds many titles – performer, composer/lyricist, producer and educator. In June, he added one more – AFA fundraiser. It started with a chance encounter with a Foundation employee and ended in a shimmering cabaret performance in Manhattan's Theatre District featuring 10 performers singing songs from 18 Broadway shows.

"It was a happy coincidence," he says modestly. Morley spent more than 100 hours casting and rehearsing the show, which bore the "incredibly carefully chosen" title 'Being Present.'"

"The last thing we wanted was to be offensive. We considered words like 'remembering' and 'reminiscence.'" The practice of being present is part of a performer's training. Morley felt it was just right for the one-night-only show.

The seeds for doing a show for AFA were planted in Morley through the theatre history classes he presents around the city, a great many at senior residences. He focuses on one show for each class, presenting its

history and musical selections. A woman with Alzheimer's who came to the classes with her husband had been a Columbia University professor with three degrees, but over the course of the year she attended she always sat unresponsive and seemingly unaware. That changed the day he presented "South Pacific." That day she sang and mouthed the words to all the songs.

"Music has the power to take you back," he says, adding that he has had audience members with memory loss illnesses suddenly tell him about having been at opening night of the show he's featuring or, even more surprising, that they had been in the original cast.

"They haven't had anyone to talk to about it for so long."

Morley was pleased in a different way at the AFA fundraiser, where members of the Foundation were in the audience at the Green Room 42.

"It's one thing to do this for a cause, but to have a group with a history of fighting that cause present in the audience brings it to a whole other level and makes it that much more meaningful."



Talking to Young Children About Alzheimer's

AFA's commitment to helping children understand Alzheimer's when it impacts a loved one continues with the publication of a second book, *Gardening with Grandma*, which features a section developed to offer guidance on how to start a discussion with a child. It includes tips on engaging the child and ways to simply explain Alzheimer's and emotional memory.

When a family member or important friend has Alzheimer's disease, it affects everyone close to them, including children, who may have trouble understanding the changes they see, as well as dealing with their feelings about them.

"The best time to talk to children about Alzheimer's or any dementia-related illness is as soon as you can," says Jennifer Reader, LCSW, SIFI, AFA's director of educational services and social services. "This conversation is about nurturing and maintaining the bonds between the family members while also helping to eliminate the fear of the unknown for children."

Children are highly intuitive. No doubt they have been picking up on changes in their loved one, but they may not feel comfortable asking questions about them. It's important to welcome questioning.

The concluding section suggests ways to share information at a level appropriate for the age and maturity of the child.

If the person with Alzheimer's can and feels comfortable doing so, have a conversation with them and the child together. The child may be comforted hearing directly from their person.



Be mindful that this type of conversation is more effective when the person is in the earlier stages of Alzheimer's and may not be possible in the later stages. If the person is unable to have this conversation, or feels uncomfortable doing so, do not force the issue.

There may be a time in the Alzheimer's journey when a person with memory loss won't know the child or remember their visits. This may be difficult for the child and make them feel worried about how to engage with their loved one. Reassure the child that although their loved one may not remember a visit or a conversation, they can still hold on to the emotions they experience, carrying with them the happy and joyful feelings they felt during their time together.



"Even young children can and should be taught about dementia. *Gardening with Grandma* is a valuable tool for helping children understand brain change and empowering them with effective responses."

— Teepa Snow, MS, OTR/L, FAOTA
Founder of Positive Approach to Care®

Gardening with Grandma and AFA's beloved first book, *Dancing with Granddad*, are available at shop/alzfdn.org.





Jake's 58 Customers Donate \$19,000 in "Change" to Alzheimer's Foundation

Customers at Jake's 58 Casino Hotel knew one way they could place bets that were guaranteed to win. No luck was needed when they invested in the "donate your change" program while AFA was the recipient. Between September 2022 through March of this year, Jake's 58 customers raised more than \$19,000.

President and CEO Phil Boyle said that total was more than any "donate your change" recipient had received in the more than a year he has been in leadership. The fundraising program is ongoing at the casino, in the Village of Islandia on New York's Long Island. Past support has gone to organizations focused on autism, veterans and Ukraine. Jake's is a public benefit corporation, one of only two government-owned casinos in the United States.

"We recognize the importance of the support and education AFA provides," Boyle said. "Your reputation speaks for itself."

He doesn't know the percentage of people who participate because the

process is anonymous. Customers playing the slot machines are given an option to donate the change part of their winnings while they are cashing out at the kiosks. The program runs during the casino's full 8 a.m. to 4 a.m. operation.

"If they win something like \$8.31, they can donate the 31 cents. That doesn't sound like much, but it adds up."

He said as president he interacts frequently with customers. Quite a few stopped him to say they appreciated that Jake's had chosen AFA. While he doesn't have any family member living with a memory loss condition, he met many people with loved ones who were affected during his years as a New York State senator and assemblyman.

"Not everyone knows a homeless veteran, but, unfortunately, almost everyone knows someone with a connection to Alzheimer's or dementia," he said.

Photos courtesy of Jake's 58 Casino Hotel



Stories, Inspiration and Wisdom from AFA Scholarship Winners

AFA's annual Teen Alzheimer's Awareness Scholarship Contest asks high school seniors to describe how Alzheimer's disease has impacted their lives, what they have learned about themselves, their families, and their community in the face of this disease, and what their plans are for bringing awareness to Alzheimer's in the future.

Students can submit entries as essays or videos. This year AFA awarded almost \$70,000 in college scholarships to 103 students from across the country who were chosen from more than 1,500 entries. Since its inception in 2008, the program has awarded more than \$430,000 in scholarships.



VINCENT YAO, Malvern, PA, FIRST PLACE (essay contest), \$5,000 scholarship. Attending University of Pennsylvania.

Over the years that [my grandfather] Yeye struggled with Alzheimer's, my mother and I devoted more and more time to taking care of him....Now, I'm working hard to learn more about Alzheimer's....As an incoming freshman at the University of Pennsylvania, I plan to join the Penn Alzheimer's Buddies, a club that pairs members with nursing home residents experiencing dementia....I hope to pursue research into the field of Alzheimer's through the Joseph Wharton Scholars Program....Most importantly, I hope to help other children, just like me in middle school, cope with their loved ones suffering from Alzheimer's. As a student who loves writing and hopes to pursue a hobby as a journalist, I plan to submit articles that raise awareness about Alzheimer's and dementia. What initially began as a way to connect with my grandfather has become a passion and an integral part of my identity.”



CLARICE NGUYEN, Gilbert, AZ, SECOND PLACE (essay contest), \$2,500 scholarship. Attending Arizona State University.

“As I enter college, I continue to find little ways to connect and assist my grandmother before I leave. I also find ways to help other senior citizens, be it playing piano with my music school at senior living centers or writing letters and making art for those in nursing homes. I look to find more opportunities like these at university, or perhaps even start them myself. One thing I am sure of is even if there is little to someone's memory other than their name and little to their abilities other than a small smile, their emotions and feelings are still so real, and that is worth any effort to bring hope and joy to their lives.”

Continued on following page

STORIES, INSPIRATION AND WISDOM FROM AFA SCHOLARSHIP WINNERS *cont'd from p. 13*

AN LI, El Paso, TX, THIRD PLACE (essay contest), \$1,250 scholarship. Attending University of Texas, Austin.

“Each time a vulnerable moment was shared with me, or I had found a new opportunity to inspire change, I am reminded of my grandpa’s legacy. Although I lost him, I will never lose what he instilled within me: the ability to persevere through any hardship. Pocky’s slogan—to share happiness—has become my ultimate mission in life. (Pocky is a Japanese chocolate-covered biscuit stick.) I hope to continue channeling these same essences in my future career as a reformer, where I’ll work to bridge the gap between the inaccessibility of dementia resources to willing families and caregivers.”



MATTHEW AASEN, Chantilly, VA, FIRST PLACE (video contest), \$5,000 scholarship. Attending Belmont University.

“The biggest thing that has stuck with me is the music she [my grandmother] inspired in me and gave me the confidence to make. In the future I’d like to bring more awareness to how music can help bring those with Alzheimer’s peace, comfort and happiness just like it did with my halmeoni [grandmother]. I’ve learned that when everything is forgotten music can remain. Now I’m planning a music business degree as well as a career in the music industry, and I wouldn’t be at that point without my halmeoni.”



CHARLES BLACK, Portland, OR, SECOND PLACE (video contest), \$2,500 scholarship. Attending MIT.

“Grandma has been an important part of my life and it is now time for me to help her. Through this process I’ve found my calling to pursue medicine and help others partly because of my grandmother. I’m infused with a passion to study neuroscience and finding a cure for dementia. I have great potential and plan to do biomedical research in neuroscience and become a physician scientist to help find a cure for this devastating disease. My biggest contribution, I believe, will be through my career and love of my grandmother.”



MADELYNN COY, Avon, IN, THIRD PLACE (video contest), \$1,250 scholarship. Attending Kelley School of Business, Indiana University.

“I have really seen first hand what it takes to take care of Alzheimer’s patients. Watching my mom be their [my grandparents] primary caregiver is really difficult for me because I don’t understand why there aren’t more resources provided. I plan to be an Indiana senator and I believe that being in local government I’ll be really able to input so many resources and programs to provide for the elderly community that we all kind of set aside. The more resources we have and the more funding we have the more likely that someone else won’t lose their best friend.” ■



To learn more about AFA’s Teen Alzheimer’s Awareness Scholarship, go to ALZFDN.ORG/SCHOLARSHIP.



What's Inspiring Us

Landmarks "Light Up in Teal" To Show Support for the Millions of People Impacted by Alzheimer's

More than 1,000 landmarks in all 50 states and 13 foreign countries inspired hope as part of AFA's Light the World in Teal annual awareness campaign on November 2 this year, part of November National Alzheimer's Awareness Month.

"Every site that participates in this global initiative is making a difference in the fight against Alzheimer's disease—and the more that join, the more awareness we will raise about Alzheimer's," said Charles J. Fuschillo, Jr., AFA's president and CEO.

Skyscrapers, office and government buildings, bridges, tourist attractions, concert halls and sports complexes all took part. These include the Empire State Building and One World Trade Center in New York City to LAX Airport, Met Life Stadium in NJ, the General Motors Building in Detroit and the Governor's Mansion in Baton Rouge. Internationally, participants included the Clock Tower at Banbridge Town Hall, Northern Ireland; the Sky Ribbon Bridge in Australia; and the Emirates Spinnaker Tower in the UK.

To see the complete list of participants, go to lighttheworldinteal.com. Organizations interested in participating next year can learn more here as well or contact the Alzheimer's Foundation of America at 866-232-8484. There is no fee for sites to participate in the program.





ALZHEIMER'S FOUNDATION OF AMERICA
322 Eighth Avenue, 16th Fl.
New York, NY 10001

Did You Know?

MORE THAN 6.7 MILLION individuals are living with Alzheimer's.

Each year, **MORE THAN 16 MILLION** Americans provide more than 17 billion hours of unpaid care for family and friends with dementia.

The number of people in the U.S. living with Alzheimer's is projected to more than double to **14 MILLION BY 2060.**

Source: Centers for Disease Control and Prevention

Give them help.
Give them hope.
Give today.

Please donate at
alzfdn.org/donate

