

AFA Care Quarterly[®]

For caregivers of individuals living with **Alzheimer's Disease** and related illnesses
A publication of the **Alzheimer's Foundation of America**



**Dr. Jonathan LaPook reflects on his
60 Minutes Alzheimer's Feature**

 | SUMMER
ALZHEIMER'S FOUNDATION OF AMERICA | 2018

FEATURES



PAGE 2
Teammates



PAGE 8
The Story Behind the 60 Minutes Story



PAGE 12
Seizures in Individuals with Alzheimer's



PAGE 14
Respect



PAGE 16
Selfless Love



PAGE 18
The Special Bonds

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Front Cover: Dr. Jonathan LaPook / CBS News / 60 Minutes

A MESSAGE FROM OUR PRESIDENT & CEO



“The strength of the team is each individual member. The strength of each member is the team.” —Coach Phil Jackson

Coach Jackson’s words apply just as easily to caregiving as they do to basketball. Successful caregiving teams depend on each other to succeed. Each individual member does their part, works hard and raises their teammates higher. They recognize that they are stronger and more effective together than they are on their own.

AFA is here to be part of your caregiving team. We work hard every single day to provide the support and resources you need to handle the challenges of caregiving. Whenever you need a teammate, please remember that we’re here to help.

The Summer 2018 issue highlights some of the “teams” that are working to make a difference for the millions of Americans affected by Alzheimer’s disease.

Our cover story features an extensive exclusive interview with CBS News chief medical correspondent, Dr. Jonathan LaPook, whose 60 Minutes piece captivated the nation with the chronicling of a couple’s decade-long journey with Alzheimer’s.

Former Major League Baseball All-Star Shortstop, Bud Harrelson, who publicly revealed his Alzheimer’s diagnosis earlier this year, and his family talk openly about how they are tackling the challenges of Alzheimer’s disease together. “Team Harrelson” is sharing their story to raise awareness and help others who are going through the same experience.

We look at how a research team at NYU Langone Health is studying the parallels between Alzheimer’s disease and epilepsy. Their goal is to find ways to eliminate or reduce seizures in those living with Alzheimer’s disease to improve quality of life and slow the disease’s progression.

Finally, you can read the moving stories submitted by AFA’s Teens for Alzheimer’s Awareness Scholarship Essay Contest winners. These amazing students share how Alzheimer’s impacted their lives and why they are now part of the team fighting this disease, which does not discriminate.

We hope you enjoy these stories and the other information included in this AFA Care Quarterly issue. As always, we welcome your feedback and ideas for future stories. Share them with us through email at info@alzfdn.org or write to us at 322 8th Avenue, 7th Floor, New York, NY 10001.

Take good care,

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

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TEAMMATES

Baseball legend **Bud Harrelson** and his family share their Alzheimer's story

In 16 seasons as a major league shortstop, Bud Harrelson earned a World Series ring with the 1969 “Amazin’” New York Mets, a gold glove and two all-star selections. Widely known for his tenacity and grit, he famously fought Pete Rose in Game 3 of the 1973 National League Championship Series. Now Bud is standing up to a new foe; Alzheimer’s disease. Just like on the baseball diamond, he’s not backing down.

Earlier this year, Bud publicly disclosed that he is living with Alzheimer’s disease. He and his family, Team Harrelson as they refer to themselves, decided to go public in order to raise awareness and help others living with the disease.

“I know I’m not alone. There are a lot of people out there just like me who have this disease. We want everyone to know that you can live with Alzheimer’s,” Bud said.

Bud and two other members of Team Harrelson, his ex-wife, Kim Battaglia, and their daughter, Kassie, spoke at AFA’s Educating America Tour stop in New York City this past May.

Before a crowd of more than 300 people, they candidly discussed Bud’s diagnosis, his life with Alzheimer’s disease and how they are helping each other along the journey.

Bud’s Alzheimer’s story started long before his diagnosis. Several years ago, Bud was becoming more forgetful, had trouble remembering words and at times was unable to finish a conversation. Concerned, Bud’s family encouraged him to visit a doctor, which he did in 2013. The physician attributed the symptoms to depression and anxiety.

“We were actually excited by that diagnosis because there is a treatment and cure for those conditions,” said Kim. “And they made sense to us. At the time, we were separated and I had moved out of the house, so a lot of the household responsibilities now fell on him.”

“But then a few more years went by and nothing was changing,” she added.

In some ways, the symptoms actually grew worse; Bud started getting lost while driving to familiar destinations. In 2016, he visited a different doctor, who diagnosed him with Alzheimer's.

"In that moment, it was devastating," said Kim.

"It was for me," Bud added. "I didn't know what Alzheimer's disease was. But I do now."

While they were certainly hard to hear, the doctor's words provided the family a sense of relief in finally knowing the true cause of Bud's symptoms.

"The initial diagnosis was really hard, but it also let us know what we were facing," Kassie said. "And now we can come together and do what we need to do as a family."

"Along with the relief of finding a diagnosis of something you've been questioning for a long time came fear," described Kim. "And our first thought was, 'what do we do now?'"

Team Harrelson began by educating themselves about the disease, including speaking with staff from AFA.

"For me personally, whenever I have anxiety about something, it's usually based on fear of not knowing what to do. So any action we were able to take in the direction of doing something took away some of the anxiety," Kim added.

One of the things they learned is the importance of social interaction, physical exercise and diet in slowing the progression of the disease. Addressing those issues was their next step. The family incorporated an exercise regiment and changed Bud's diet to remove dairy and sugar.

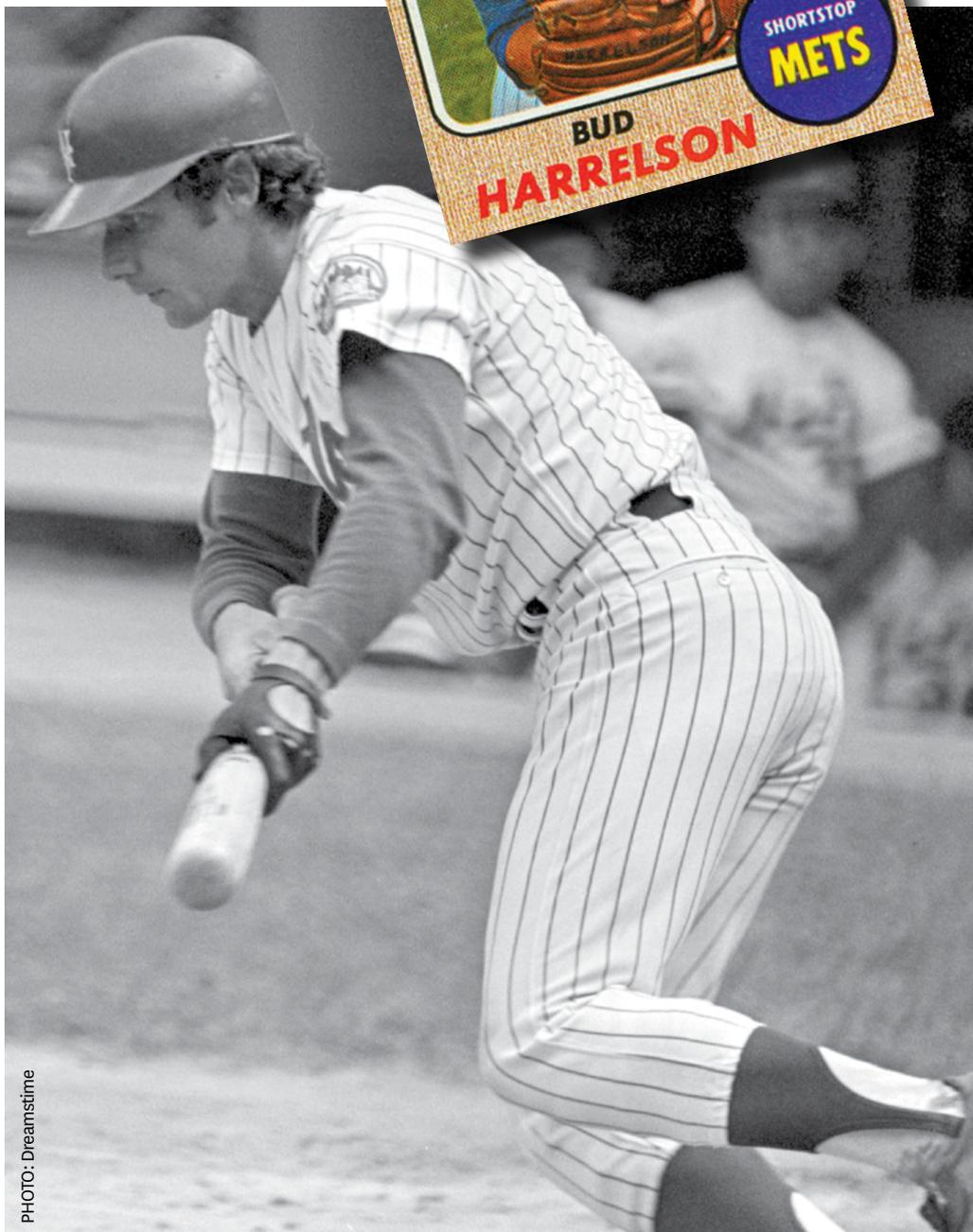
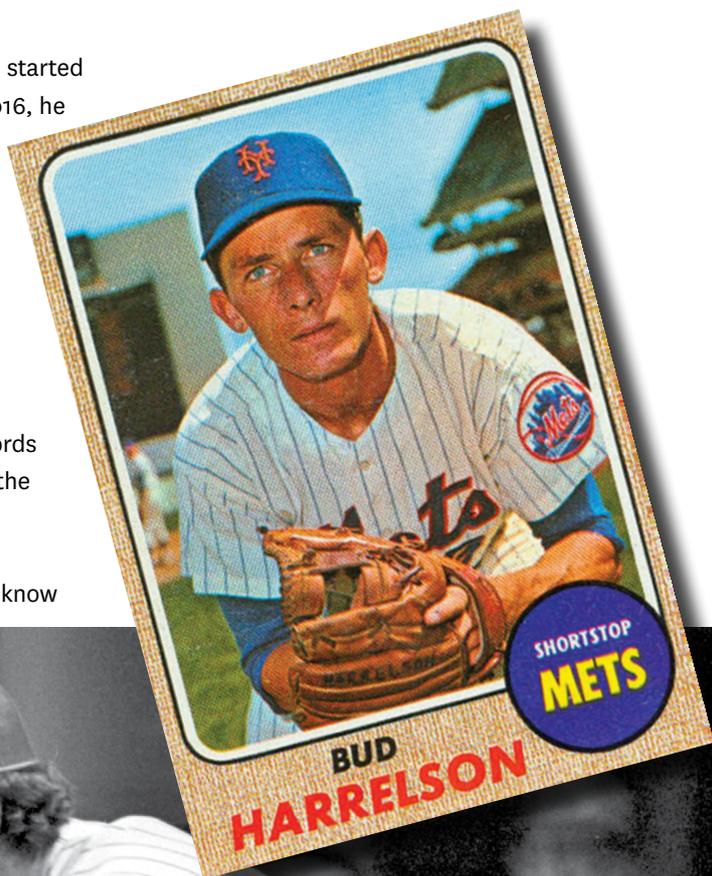


PHOTO: Dreamstime

They also keep him socially active, including making sure he was still able to take part in activities with the Long Island Ducks, an independent league baseball team. As a long-time coach and co-owner of the team, the Ducks organization has a special place in Bud's heart.

"Bud's interaction with the Ducks has been paramount. It's helped him keep a routine and feel productive and needed," Kim stated.

For others who are caring for a family member with Alzheimer's, Team Harrelson stressed the importance of having a strong support system.

"Our children, extended family members and friends all pitch in. We have caregivers who are companions that will spend time with Bud, do things like take him to lunch and help with



"I still go to the ballpark everyday." Bud Harrelson with AFA Founder and Board Chairman Bert Brodsky at the Long Island Ducks' Alzheimer's Awareness Night in 2017.

day to day stuff, to give the family time to do the things that we need to do."

In addressing some of the challenges caregivers face from her own experiences, Kim advised caregivers to not only be unafraid to ask for help, but also to be specific.

"We have so many people who want to help, but no one shows up at the door every day asking 'what can we do?' So it's important to be specific when asking for help, like 'can you come by and spend three hours with Bud on Friday' or 'can you take him to his doctor's appointment?'" she stated.

The change in the family dynamic has at times been difficult, especially for the children.

"Going from being the parent, the driver and the bread winner to a different role can be hard," Kim explained. "And it's not just difficult for the person who has the disease but for the family members who now have to assume the role of parent to their parent as well."

Bud also talked about some of his hardships, including losing some of his independence and having to give up driving, which he voluntarily did immediately after being diagnosed.

"Worst thing I've had to do," he said. "But I saw it coming, because I was getting lost a lot."

Giving up ice cream was also tough, though he admits to "sometimes cheating a little."

And he no longer throws batting practice, which he routinely did as a baseball coach.

But Team Harrelson is focused on the positive.

"I know it's still the early stage and I can see what's coming down the road, but there's still so much quality right now. And I think there will be quality no matter what stage we're in," said Kim.

"I still go to the ballpark, every day. I still feel like I can play," Bud said. "It'd be pretty cool, wouldn't it?"

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With Grace Townley-Lott, LMSW

Question:

Mom needs more help at home than Dad is able to provide.

However, they are very hesitant to accept an aide from a home care agency, and I'm not sure how to convince them. How can I get this started when they don't want the help?

This is a very important question - and a very common one. Feeling independent and capable is central to many people's identities, and before you try to get your parents on board with the plan for more care, it is beneficial to listen and validate the feelings that your parents may be experiencing regarding this change.

First, try to acknowledge that it may be challenging for them to agree to receive outside help, because it may feel like they are admitting to a loss of some kind, whether it's physical, cognitive, or social. This can be very tough for some people to do, especially those who are fiercely independent. When they start needing assistance, they may fear the snowball effect of needing more and more care from now on - and giving up more and more independence. Why would they want to agree to start a cycle of dependence now, when they could put it off?

It's good to know that while these fears are very real and understandable, this does not need to be the outcome. Sometimes, people need help for only a short period of time, like when they're recovering from a fall or a hospitalization. Others may find they welcome the extra set of hands for trickier tasks and might enjoy having someone to converse with and go with to events. In fact, having an aide there may allow them to successfully age in place, in their own home, and remain more independent, continuing to do the things they love.

If you know your parents are very opposed to the idea, one route to introduce the subject is to get a written note from a trusted doctor recommending home care (and make several copies of the note in case it gets lost). This could be a good excuse to start the conversation, and they may be more likely to consider it if a doctor they respect thinks it would be helpful.

When you start the conversation, ensure your environment is set up for success: reduce distractions by turning off televisions and music, sit in a comfortable location, and only include a small number of people in the room so it feels less overwhelming. Free up your schedule so you don't feel rushed. If your parents need to use the restroom frequently, it can be helpful for them to take care of this need first so you're not interrupted mid-conversation. Make it a friendly chat; perhaps everyone would feel more comfortable with a cup of coffee or tea in hand.

Use a caring, non-threatening approach during your conversation. Ensure you hear and acknowledge your parents' concerns. Write them down, because you can bring these concerns to the home care agency and ensure they are addressed. Ask your parents how they feel things are going in the home.

Talk about why you are worried about them. It may be that they are willing to try out some services to help put your mind at ease. This way, it becomes a situation in which they are doing you a favor, to help you sleep better at night - rather than admitting that their situation is unsafe.

Ask them about their goals, instead of focusing on your own. Keep their goals in mind during your conversation. Do they want some assistance with light housekeeping? Would they like some help with meal preparation? Do they want to feel more confident and less fear when dressing or showering? Would they enjoy having a friendly face around the house to chat with? Or, while often overlooked but very important: do they want to reconnect with old passions and interests, such as art, music, gardening, social clubs, etc.? A good home health aide can help with all of these goals, and can even accompany them

to museums, concerts, theaters, parks, botanical gardens, chorus groups, art classes, and other community events.

Ease into it - but be consistent. Work with your parents to develop a reliable schedule that they can count on, even if it's just for 4 or 5 hours a day. Starting out with a few days a week may be less intimidating, and scheduling routine events or outings that they can enjoy with the aide on those days may be helpful. If their aide helps them get outside to enjoy the weather and to their favorite restaurant or activity every Monday, Wednesday, and Friday, they might even start looking forward to the aide's visit! If memory is an issue, write the aide's schedule on a large calendar in an easy-to-spot location, as well as the activities that they can look forward to.

Give it time. Developing a trusting relationship with a new person in the home will take time. As they get to know each other, it will become clear whether the aide is a good match. Please encourage your parents to speak up if their aide's personality isn't quite matching up with their own. Just give the agency a call and explain the situation, and they should be happy to replace that aide with someone who is a better match.

If you'd like to discuss your situation more in-depth with a licensed social worker, please feel free to call AFA's National Toll-Free Helpline. You can also encourage your parents to call to discuss their concerns; they may feel more comfortable talking to a third party about their situation. You can reach AFA's National Toll-Free Helpline at 866-232-8484.



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.

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PHOTOS: CBSNews/60MINUTES



The Alzheimer's Story

Dr. Jonathan LaPook reflects on his experience following a couple affected by Alzheimer's

Of all the segments he has produced over the years, none would touch him so deeply as a story he would spend a decade documenting. Since 2008, Dr. Jonathan LaPook, CBS News chief medical correspondent and Professor of Medicine at NYU Langone Health, has followed the poignant story of Mike and Carol Daly and their journey with Alzheimer's.

Making its debut this past April on 60 Minutes—it's said to be the longest "video study" for broadcast of its kind. LaPook chronicled the lives of the Dalys and gave us a candid and intimate look at what it's like to live with Alzheimer's—from both the perspective of the affected person and the caregiver.

Specializing in internal medicine, gastroenterology, and medical computing—LaPook joined CBS in 2006, and has contributed more than 1,000 reports to the CBS Evening News, 60 Minutes, CBS This Morning, CBS Sunday Morning, Face the Nation, and CBS Radio. LaPook has won two Emmy Awards

and multiple other honors, including a Gracie Award this year for two segments he produced for 60 Minutes.

On behalf of all the families affected everywhere by Alzheimer's, we are grateful to Dr. LaPook for his perseverance and getting Alzheimer's out front and center. We also thank him for granting this interview to AFA Care Quarterly.

AFA: How did you first meet Mike and Carol Daly? When did you realize you were on to something bigger than just a one-off story?

JL: We met back in 2008 when we were doing a story about a potential treatment for Alzheimer's. Unfortunately, that trial was unsuccessful for Carol, but after I met them the first time, I decided I'd keep coming back. He was the salt of the earth—a retired New York City cop. She was very personable and still in the early stages. When I first met her, she knew who Clark Gable was and would



say, 'OOO he was so handsome!' We were able to talk. This was a very painful time because she knew what she was losing, and she had a sense of what was waiting for her because Mike's mother had Alzheimer's, so she knew very well what was in store for her. And in fact—a couple of years later—she did not know who Clark Gable was, and a couple of years after that she did not know who Mike was.

So there were two defining arcs to this story that were apparent over the years: one involved Carol, which was predictable. We knew that she was going to have a decline, and we see upfront and personal what that decline looks

like. But the other defining arc, which is less familiar to people, is the caregiver. You see Mike at the beginning saying, 'I got this!' Some of the footage is just heartbreaking. He combs her hair and does her make-up. I said, 'boy this is not what you signed up for' and he said, 'actually it is—for better or for worse,' which was the title of our piece. So over the years, you see her decline, but you also see his decline. Mike's weight fluctuates and he develops high blood pressure, anxiety, and panic attacks. But he still insists that he won't put her in a nursing home. The big message for people watching this is: You can't do it by yourself. As a caregiver, you have to get help. The daily day in and out stress of being a caregiver is enormous.

I wasn't doing pieces for 60 Minutes back then and just thought I would keep coming back and maybe this could make a documentary some time. So later on, I went to 60 Minutes and I said how about splicing these together?

AFA: Was there anything unexpected or surprising about your experience?

JL: Yes, I'm an internist and a gastroenterologist and used to seeing patients with Alzheimer's who come to my office. But to see this all up close and personal in their home and see what it means on such an intimate and personal level—that was something that I hadn't seen before. I witnessed not only the decline that somebody experiences as a patient, but the struggles that a caregiver faces.

AFA: What do you think are the immediate takeaways of the segment? Any lessons learned?

JL: One big lesson is that you have to have the discussion with your families about your end-of-life plans and to do this when you're well. So, if I need help, is it okay if I bring in outside help? If it gets so hard for me that I can no longer care for you at home—can I bring you to a nursing home? What about long-term care insurance? Do we have enough of it? Everyone thinks they're going to live forever. We are not great in America about discussing end-of-life issues and what to do if we get sick. I think that these are really honest conversations that people need to have when they are well. The time to have them is when you're in your 30s, 40s, 50s and to keep revisiting. You're always free to change your mind about something, but you should keep that dialogue open, so that people aren't left guessing and that Mike is not thinking...well gee, is it okay if I bring her to a nursing home? Would she have wanted him to bear the burden by himself? Probably not. The three themes in the piece are: the obvious decline of the person who is ill; the stress and decline in the caregiver; and the need to communicate early on and plan for the future.

AFA: What kind of response have you received since your 60 Minutes piece aired?

JL: This is the biggest reaction I've ever had to any piece. I'm hearing from people from all over. It hit a nerve. And I hope it continues to make a difference.

AFA: We read that after Mike Daly admitted on camera that he had suicidal thoughts that you evaluated him immediately afterward (off-camera) as a physician to ensure that he wasn't really suicidal. Could you tell us about that experience?

JL: When I went back with the 60 Minutes crew, Mike shared that a couple of months earlier he was feeling so badly that he thought of putting a gun to his head. And, boy, that took my breath away, because he's a former cop and I knew he must have a gun. So that was the point where I had to click out of journalism mode. And after the cameras were turned off, I talked to him and I said, 'are you suicidal?' I really felt that I had to figure that out. And he said he wasn't and that he had spoken to his doctor about his feelings and was no longer suicidal. And I said make sure you continue to talk to your doctor about these kinds of feelings; I'm not your doctor. He started feeling better once he finally started getting help in the house and getting out more. And finally—we didn't have time to put this in the piece—we had said that Mike put her in the nursing home—but what we didn't have time to cover was that a couple of weeks later, he was feeling better and she was actually feeling better. She was sitting up straighter in the chair because she had more attention. Now, he is feeling less badly. He was so guilty early on about putting her in the

nursing home. But it turns out that he's happier and she's happier, but still—this piece just sucks the air out of you. It's gut-wrenching.

AFA: Out of all the medical stories over the years that you've covered as a journalist, how did this compare? Did this story feel the most personal and why?

JL: I never had any story where I became as emotionally involved over such a long period of time as this. So far, no one has told us that there has been a similar follow-up like this. Ten years is unique, but I think it's very instructive and again, it is an Alzheimer's piece, but it's really a caregiver piece. And I think we need that right now.

AFA: Have you been touched by Alzheimer's personally?

JL: Yes, Alzheimer's affects everyone. I recently heard from a close college friend of mine in his early 60s whom I emailed about the upcoming piece, just prior to broadcast. He responded saying 'thanks for letting me know, as luck would have it, I was just diagnosed with Alzheimer's a couple of weeks ago.' If there are 5.5 million people with it, for every person with Alzheimer's, there are



probably another 10 people at least who are affected by that one person having Alzheimer's. So we're talking about tens of millions of Americans and rising.

AFA: As a physician and a journalist—you've likely encountered patients and their families over the years who were not always so open and willing to share their story with the world, as well as others like the Dalys, who seemed motivated. What has your experience been in this regard?

JL: The very first time we met Carol and Mike, they were both vehement about wanting to bring attention to this and to show it up close and personal. I'm always concerned with a story like this: are we getting consent and is she cognitively able to give consent. Her neurologist felt that she had the ability to give consent. She

was absolutely able to have a conversation with me the very first time we met, and she was very clear about her interests. And then throughout the years, Mike kept saying 'let's give this more attention; people need to know and see what this is like.' That's kind of been my experience, in general. I did a piece a few years ago with three generations of women in a family with a strong genetic link. They wanted attention. People are desperate and they feel there's not enough research and there's not enough attention. They want to do something now and they are willing to be the face of it. And I think they are very brave. I owe a lot to Mike and Carol and I'm very grateful to them because they let us into their lives and helped to put a face on this, including Mike who has helped put a face on caregiving and all the struggles that people have.

AFA: Assuming you're able to share, where do you see your next 60 Minutes Alzheimer's piece headed in terms of angle, content, and direction? What aspect, in your view, could use more attention?

JL: I'm going to keep following Carol and see her at the nursing home. Many people, I think, tend to be biased against nursing homes. Let's see what a good facility looks like, and how our loved ones could be taken care of well. You sometimes hear horror stories about nursing homes, but they can be extremely helpful, and we have to take the stigma away, while at the same time making sure that there is a good level of care. Mike shouldn't have been so terrified about sending Carol to a nursing home. It turns out that there could be a lot of stimulation in the nursing home. The quality nursing homes engage their residents with music, art, reminiscence therapy, and other activities. This not only makes the person living with dementia happier; it takes the pressure off of the caregiver.

AFA: How might your role as a physician help or present challenges when covering such a story?

JL: The best example of feeling a conflict as a doctor was when Mike felt so bad that he had suicidal thoughts. As I shared earlier, I flipped into doctor mode to make sure he was no longer suicidal and that he had told his physician. Also, occasionally, he would ask me medical questions. I'd say, look, I'm not your doctor or Carol's doctor, but you're asking me, so please make sure you check with your own doctor on whatever I tell you. I do walk a line between journalist and physician, and I can't always be perfect. If I notice something as a doctor; if they are confused about medicine or something and they have a question about it, I might answer it, if I'm sure of the answer. But I am also a doctor, and there are times when you definitely hit the pause button on journalism and say, you know what: I must be the doctor here right now. That's more important.

The Giving Corner

Donate Your Birthday



Birthdays are special occasions. They are opportunities to spend time with family and friends, as well as receive gifts. Social media now has a tool which allows people to turn their special days into days of giving, not just getting.

Last year, Facebook launched a “donate your birthday” feature which allows individuals to easily use their birthday as a way to encourage charitable giving. In short, it allows people to celebrate someone’s birthday by celebrating the cause that is near and dear to that person’s heart.

Users normally receive a request from Facebook about 2 weeks before their birthday asking if they want to create a fundraiser. They can also create a fundraiser at any time themselves for birthdays or other occasions (see instructions on how to do that later in this article).

Many Facebook users have embraced the feature to support a variety of causes, including Alzheimer’s disease. As a participating charity, AFA has received thousands of dollars in charitable gifts through the platform since the beginning of 2018.

The service is free and Facebook does not charge a fee to nonprofits, meaning that everything raised through your birthday fundraiser will go to your charity of choice. At the time of this writing, Facebook was even making donations to users who set up birthday fundraisers to help them get started!

When your special day rolls around, consider celebrating with your Facebook friends by helping families affected by Alzheimer’s through supporting AFA. Regardless of whether you raise a lot or a little through your birthday fundraiser, you will make a difference!



Donating your birthday on Facebook is easy! Follow these steps to set up a Facebook fundraiser for AFA:

1. Click Fundraisers in the left menu of your News Feed.
2. Click Raise Money for a Nonprofit Organization.
3. Select AFA as your charitable organization of choice.
4. Fill in the fundraiser details and choose a cover photo.
5. Click Create.
6. Encourage your family and friends to participate!

To learn more about setting up a Facebook fundraiser, visit www.facebook.com/fundraisers

SEIZURES

SEIZURES

in Individuals with Alzheimer's

Researchers at NYU Langone Health exploring ways to prevent them

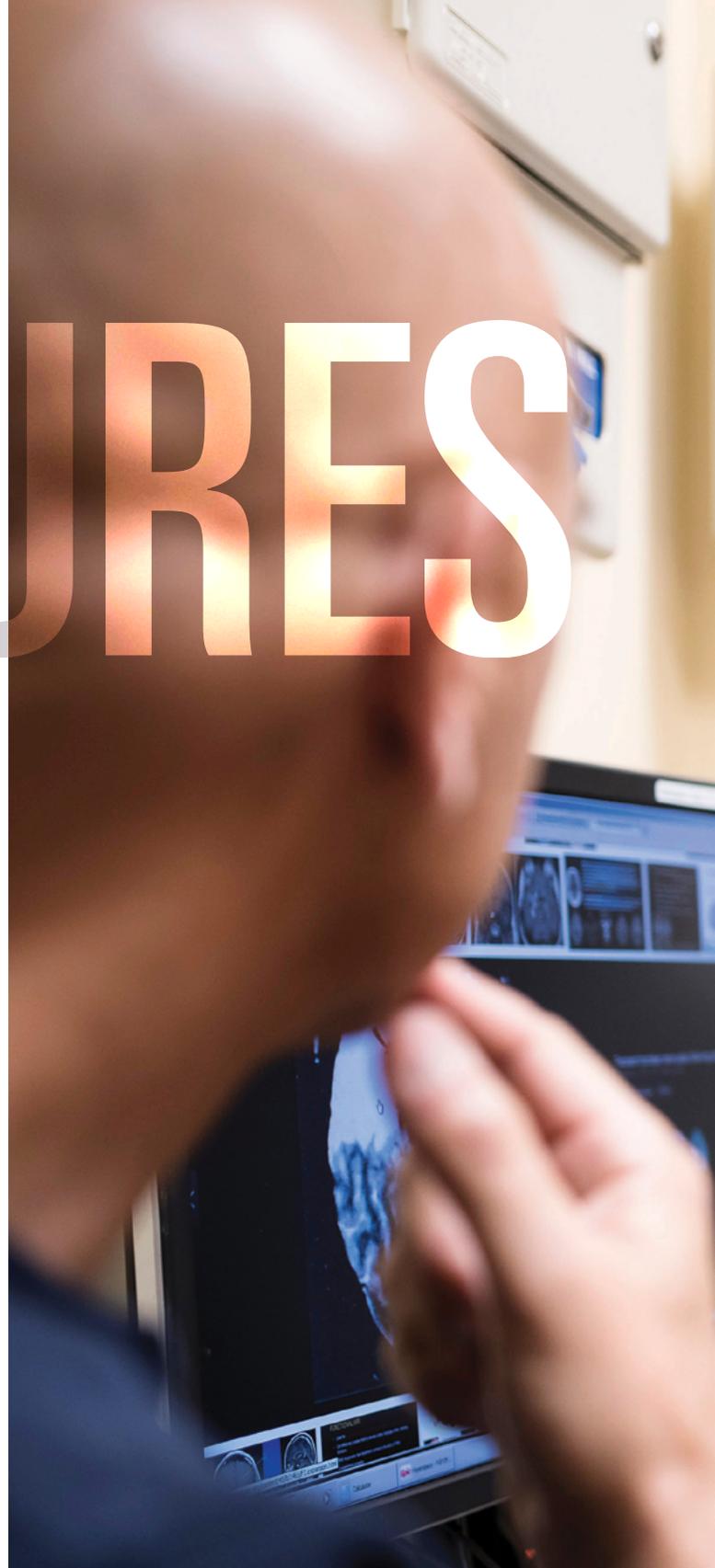
Epilepsy and Alzheimer's disease (AD) frequently co-exist. The former may contribute to the progression and the more rapid decline of an individual living with AD—making early epilepsy identification and treatment critical.

What makes some people with acquired brain disorders go on to develop epilepsy—while others do not? To find out—potentially leading to more targeted epilepsy treatments—Orrin Devinsky, MD, and his team at NYU Langone Health in New York are currently investigating biomarkers of the disease. AFA provided grant funding to support the team's work.

Dr. Devinsky is Director of NYU Langone's Comprehensive Epilepsy Center. He is also a Professor of Neurology, Neurosurgery, and Psychiatry at NYU School of Medicine.

“Interestingly, the process of developing epilepsy parallels Alzheimer's in that in some cases, it involves the same two pathologies long thought of as the primary causes of Alzheimer's—amyloid beta and tau,” says Devinsky.

In this prospective study, the information of tens of thousands of people living with AD over a number of years, including clinical, imaging, and cognitive function data, will



be leveraged to identify these biomarkers. The available data comes from two large community-based groups—the Framingham Heart Study (FHS) and Rotterdam Study (RS).

Dr. Devinsky says, “Given our aging society, the incidence and prevalence of late-onset seizures is expected to rise substantially, making late-onset epilepsy a condition of



PHOTOS: CBSNews/60MINUTES

PHOTO: John Karsten Moran

Dr. Orrin Devinsky

significant public health importance—both when it coincides with—and is independent of Alzheimer’s disease.

For people living with Alzheimer’s, eliminating or reducing seizures could slow Alzheimer’s progression and improve their quality of life, the ultimate goal of medicine until we can cure Alzheimer’s,” he adds.

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Respect

By Laurence Crandon

Imagine a muscular distinguished elder with bright white hair, who commands the room when he walks in. Years of playing professional Negro League Baseball, well into his late forties, with players like Satchel Paige, Josh Gibson and Larry Dobe, had left him strong as he aged. Years of combatting Jim Crow, being spat on, called boy while wearing his Navy uniform, and relegated to an eighth-grade education, had left him strong in mind yet full of grace and poise. And that voice. That baritone espresso rich voice addressing me as, “My dear fellow” as if he were Prince Charles from England, not William “Sonny” Randall from Hampton, Virginia. That voice always found an audience, sometimes willing spectators and sometimes captive (i.e. in a restaurant, at the doctor’s office or even an elevator) to hear him belt out Frank Sinatra’s greatest hits. “And now, the end is near, and so I face the final curtain”, was one of his favorites—My Way. Admittedly, I was embarrassed because he would

just start singing. Anywhere. Everywhere, without inhibition. When I lifted my head from wanting to crawl into a corner, I saw startled patrons, patients and staff would be listening with rapt attention, delighted by his tone, pitch and voice quality at 92 years old. My shame turned into pride as I saw how much joy he brought to people. That’s my Papa. Wise, wonderful, gentle, a man of few words but who commanded quiet power.

Once Papa and Grandma moved in with us, I began filling the role of afternoon caregiver—making sure they ate, were safe and comfortable--after school. An avid reader, Papa was well versed in world affairs and would have conversations for hours about how things used to be. He marveled at the opportunities that my brother and I had through education and often wondered aloud what life might have been like if only he had those opportunities. That’s one of the reasons I work so hard to succeed, to honor his own sacrifice and to prove that with a level playing field and opportunity, everyone can be great.

As time went on, conversations with Papa took strange turns. He would forget what day it was. He would get up in the middle of the night. Usually unphased by anything, he became irritated by small things. I don’t think any of us slept soundly for three years, always fearful he would tumble down the stairs in the dark. My room was directly across from his so I jumped up at the slightest sound of movement. Sleep deprivation took a toll on us all. At one point, we started leaving the previous day’s newspaper downstairs so that when he was prowling at night, he wouldn’t want to go outside in the dark to get the newspaper from the driveway, which would be dangerous. I thought our newspaper tactic was a cruel trick at first but sadly, he never noticed the date change or that he had read the same articles just a few hours earlier. We had to be clever like that, all the time.

At first, when Papa would dispute obvious facts, like we lived

in DC not MD, or that he was due to drive the late Senator Ted Stevens to an appointment (like he did many years ago as a chauffeur), we would challenge him with the truth. “No, Papa, we live in Clarksville, MD.” He grew combative. My gentle giant grandfather became enraged and thought we were calling him a liar. That hurt me deeply. “Senator Stevens passed away, Papa, 3 years ago”, we’d say and it’s as if he was reliving the grief all over again. “Oh no.”, he replied, his face showing a frown. Painful, again. Some of the worst battles were over taking medication and changing his clothes. Over time we learned to tell little white lies to keep the peace. “Yes, Senator Stevens is waiting for you,” I learned to eek out of my mouth, against all I was taught was right from wrong. And just like that, instead of a 30-minute heated back and forth, the conversation ended peacefully and he was on to the next topic.

Alzheimer’s is a cruel, cruel disease. It’s as if the person you love dies twice. There is grieving before there is grieving. And each milestone is a new low—forgetting dates, places, how to bathe and eat, and people. It robs you of the very essence of who you are. And it’s as if a ghost is living with you. Sometimes I had to do my own reality check to see what world I was living in. I remember one summer day, Papa had my mom convinced that two young men, strangers, had stopped by the house and had “such a pleasant conversation”. When she probed whether it was my brother and me, “You mean Randall and Laurence?”, he was adamant, “No. Two young men from the neighborhood, sat right out there with me”, pointing to the patio. My mom asked everyone in the house whether they had seen Papa talking to anyone. When my brother and I said it was the two of us, she broke down and cried.

I grew sad that such a good man would face such a grim fate. I cried often as he deteriorated and eventually forgot my name and the tapestry of stories of his youth whose precious memories molded me into who I am today. His melodies still ring in my ear, like a legacy of life lessons. “Every time it rains it rains, pennies from heaven. Don’t you know each cloud contains, pennies from heaven?” I find myself humming that when I’ve run into a bit of bad fortune and it cheers me up. “Oh Lord, my God, when I in awesome wonder, consider all the worlds Thy hands hat made...How great Thou art!”, is in my head when I see something amazing like Niagara Falls.

I expanded my responsibility helping Papa walk down the stairs-step-by-step or picking him up from the floor when he fell. Alzheimer’s impacted us all. My dad strained his back lifting Papa and would go in his room and cry after realizing Papa, his own hero, was not the same. We all pitched in, helping him to bathe, use the toilet and get dressed. He was a proud man who had shriveled to



Laurence Crandon earned a \$5,000 college scholarship as the grand prize winner of AFA’s 2018 Teens for Alzheimer’s Awareness Scholarship Essay Contest. A resident of Clarksville, Maryland, Laurence will be attending the University of Southern California this fall pursuing a degree in finance.

near bones, so much so that his dentures no longer fit and his face grew gaunt. The very soul of him was somewhere else. And, after he passed away, I was simultaneously sad and relieved for him because the worst moments were when he realized something was wrong with him and he apologized for something he truly could not help. I would hug him. Reassure him. And tell him I love him. Devastation, indescribable heartache and a grave sense of loss accompanied me for a long time after Papa died.

Through this process I have learned about compassion, patience and that in the end, all you have is family. When I had conflicting demands on my time like practice for sports or school plays, I was tempted to rush Papa but didn’t. I learned to appreciate the small things in life, like days when he was completely lucid, like the old Papa, if fleeting. My family came together, leaned on each other and strengthened each other by keeping humor going during tough moments and appreciating what each other did to help Papa. I learned it’s OK to cry.

My life has forever changed because of Alzheimer’s. I find myself looking for signs of it in my grandmothers and parents. I encourage them to keep their minds sharp, take vitamins and exercise. And I urge my friends to do the same with their parents. I happily rode the pine on my football team to prevent CTE and early onset dementia. And I have contributed to fundraising efforts through my mom’s sorority, Alpha Kappa Alpha.

Whatever can be done to stop this cruel, debilitating, dehumanizing process, please find a cure. What families and the one diagnosed have to go through is heart-wrenching. Let there be no more ghosts of people we love living among us. PLEASE, for my grandfather’s sake. Until I began writing this essay, I hadn’t realized that I had never really identified my emotions about Papa and how much his life impacted me. I am truly grateful that I had the chance to care for him, show him how much I love him and maintain his dignity. “Respect, my dear fellow, is all you have in life”, he would say. I hope I am earning his respect as I share a little bit about his life, our experience, and my desire to put an end to the disease that claimed his life.

Selfless Love

By Dani Moore

*AFA Scholarship Essay Contest
First-Runner Up*

Growing up, I was aware of what Alzheimer's disease was and its effect on people. But it wasn't until my freshman year of high school that its meaning truly came into effect. Before that, I had been blissfully ignorant of sickness, disease, and death, and the impact they have on families. All three of my grandparents had been relatively healthy, no sign of any real danger looming over their heads. That is until we found out that, no; not quite all of our grandparents were healthy. My grandmother was diagnosed with Alzheimer's. I'll be honest, the news didn't exactly shock or surprise me. I'll be even more honest and say I wasn't devastated or sad, or really any emotion close to it. Despite my grandmother living only a 30 minute drive away, we weren't close. She had always been quiet, reserved. To this day, I still can't recall a genuine, one on one conversation with her. So instead of grieving, I proceeded on with my life, cheerfully content in my little sphere of indifference.

As the years went by, her symptoms increased. I heard my parents talking about it more and more, and having to coach us on what to do in certain situations, if they should ever come up. Her safety and well-being became a major concern, and my grandpa constantly was to keep an eye on her. Finally, during my sophomore year, tragedy struck the other side of my family. My dad's mother, who I had been exceptionally close with, passed away due to a tumor in her brain. Like my other grandmother, she'd been suffering for a long time, her pain had just passed obliviously over our heads. At this point, I started to realize I didn't really have a grandmother anymore. One had passed away, and the other didn't know who I was.

Symptoms worsened. My grandmother, who had previously always been very independent, couldn't be trusted to go on walks by

herself anymore, or cook by herself, or go to the library. My grandfather became tied to her side 24/7, having to help her with all her daily tasks. It got to the point where she couldn't dress herself or go to the bathroom anymore without supervision.

She'd always been very docile, I can't remember a time where she lashed out at anyone, or showed really any sign of anger, annoyance or disapproval. So it was a bit of a shock when she began to fight against my grandpa, who was trying his best to help her. She became irritable, annoyed, and would argue and get angry with my grandpa in front of us. Sometimes my parents would have to intervene and calm my grandmother down, and take care of her until she settled down back into her old self. The words "care facility" and "nursing homes" became more and more frequent, at first spoken in whispers, then casually voiced around the dinner table.

It was inevitable that it should happen. My grandfather fought hard to keep her, but his energy was slowly getting drained by having to monitor her every hour. Finally, he agreed that a nursing home would be the best home for her, where she could be safe and around professionals in an environment built for her. I have no doubt it was hard for him. They'd lived together for more than 50



years, having nothing but each other's company. No one would ever willingly and happily send off their soul-mate to a new home 30 minutes away.

Due to the lack of medical resources in their small town, she came to ours. My parents spent hours going over medical care homes, determined to give her only the best. They moved her down to an estate that was a seven minute drive away from our house, close enough to reach her if anything should ever happen. Life went on. I entered my junior year of high school, got a job, and involved myself in school sports. I lived like any typical high school kid, paying no attention to the disease that was shattering my grandparents' world. It wasn't until my senior year of high school that my world started to really expand and I started to pay attention to and respect my grandfather and what he did to help my grandmother and her disease.

The lengths he went to care for her still amaze me. He was there with her from the beginning, and stuck by her side every step of the treatment. Even when she kept him up at night. Even when she pushed him away and refused to let him help her. Even when she no longer resembled the woman he met so long ago, the woman who he had fallen in love with and started a family. To me, that's an entirely different genre of love. That's a selfless, pure sort of love, a love stretching on further than just romantic or platonic. That kind of love, that kind of devotion, was foreign to me before I witnessed my grandma's downfall. It surprised me. It still surprises me.

As a teenager who's been in my fair share of relationships, I've never experienced anything even close to the love and utter devotion that my grandpa has for my grandma. That's love at a whole other stage in life. It really makes you question; after the thrill of new love has worn off, after the honeymoon phase, after being together for years, are they still going to love you? Are they still going to be loyal, and by your side, even in sickness or in health, as the marriage vow decrees? When your body wilts away, and your body begins to sink into old age, will they still love you the same? Thanks to my grandpa, I can say: yes. That kind of love does exist, and it's still very prominent today, if you only open your eyes and see it.

The selflessness and kindness given to my grandmother wasn't just limited to my grandpa. My mother would visit her at least once a day, take her to see shows, go on a daily walk, to attend mass, or go on breakfast dates. Even though my grandma could barely speak and didn't know who she was, my mom remained patient and true to her cause. Despite her memory being lost, the mother-daughter relationship still flourished.

Quite honestly, my grandma was given a plethora of support, from her husband, to her children, to her friends, and to her grandchildren. It really is touching to see people rally together to support one another. The kind of love that my grandpa, and my mother, and my aunts and uncles give her is selfless. They know she can give them nothing in return, not even a glance of recognition, but they give anyway. They love her because she's their mother, their spouse, their friend. Instead of trying to live in the good old days, and get lost in nostalgia, they live for the moment, and they make these memories the special ones. They treasure the time they have with her now, and make the best out of a heartbreaking, terrible situation.

I've also started to look into my grandma's life, and examine her from a whole new perspective. Lately, my family has been really starting to open up about her, about how she was when they were growing up, and who she was before her disease. She was a stay at home mother of five during the day, and a nurse for the local hospital during night shifts. She was always on her feet, always



Dani Moore of Pendleton, Oregon received a \$2,500 college scholarship as the first-runner up of AFA's 2018 Teens for Alzheimer's Awareness Scholarship Essay Contest. Dani will be attending Blue Mountain Community College for a year in the fall, and then plans to transfer to the University of Idaho to study art and writing

doing something, never taking a sick day in her life. She loved watching football, loved to travel, and always took the time to bake every kid a pie on their birthday. Learning all this was almost like meeting a new person, someone I'd never encountered before. The reason I'd never really had a relationship with my grandma was that she had been diagnosed with Alzheimer's before I was even born. Because of her disease, I had entirely missed out on the opportunity of having a relationship with her, and the chance to truly meet her.

There were positives that arose out of the negative, however. To this day, my grandpa is still the most selfless person I know. Having my grandma diagnosed brought to light a new side of him, a side I'd used to overlook. He is honestly the only person I know who gives and gives and gives, yet expects nothing in return. It's a bit odd, that something that would be seen as a tragedy was almost the opposite for my family. Our bond improved drastically, instead of falling apart, we fell together, and leaned on each other to support and love my grandmother. I may have lost a grandma, but I gained a relationship with not only my grandpa, but my aunt and uncles, and my parents. And that kind of relationship is special. It's....selfless.



The Special Bonds

By Brooke Serra

AFA Scholarship Essay Contest Second-Runner Up

Confusion, heartbreak, and loss are some words that describe the unfortunate impact that Alzheimer's disease has had on my life. However, words like growth, loyalty, and value of life describe what I gained. Alzheimer's disease has had an impact on me since I was a very young child and is part of what has made me who I am today. My great-grandmother began to be affected by Alzheimer's disease before I was born, so my only memories with her were of when she was sick. For about a year and a half, before she was moved into a nursing home, my great-grandmother began to show signs of dementia. Gradually, daily tasks became more and more difficult for her to accomplish. She began forgetting whether or not she took her medicine and she often got lost or could not remember how to get home. The decision of whether or not to move her into a nursing home fell largely on my mother. This was due to my grandmother not taking any responsibility for my great-grandmother and her illness. As an adult daughter, my grandmother was not able to cope with

the drastic changes happening. Because of how much my mom loved my great-grandmother, she became her primary caregiver while she was pregnant and worried about her own family as well. The whole time she was pregnant with me, my mother paid the medical bills, kept my great-grandmother from getting lost, kept track of the weekly appointments and grocery shopping, and much more. She was forced to do many of these things on her own because my grandmother could not confront her mother's condition. She lived out of state and could not bring herself to face what was happening. Eventually the decision was made to move my great-grandmother into a nursing home at the age of 82. While she was still fairly independent, she required the assistance of nurses in order to keep her safe. Moving her into the nursing home forced my grandmother to realize the gravity of her mother's illness and overcome her denial.

As I grew up, I learned how to aid in taking care of my great-

grandmother as well. Even though I was very young, I started to understand just how sick she truly was. I understood that she could not remember who I was, since every visit became a new introduction. I also understood that she did not know where she was since she would “go shopping,” and steal belongings from other residents’ rooms. It was scary to see her in such a confused state, but I knew that spending time with her was helpful. She always calmed down when I was there, and she always told me that she loved me, even when she could not remember my name. As a child I had a hard time being willing to go visit my great-grandmother because I did not enjoy going to the nursing home. It was a scary experience for me to be in that kind of environment as often as I was. I did not enjoy the number of confused elderly people who would approach me without warning. I was not used to so many people touching me or just walking up and talking to me as if I were their grandchild. However, I had to get used to spending time in the nursing home even if I was scared or was reluctant to be there.

Learning how to adapt to an unfamiliar, unnerving situation like that taught me a lot about loyalty, overcoming fear, and respect for elderly people who are sick or mentally disabled. I learned how to be compassionate even if someone does not understand who you

are or cannot get to know you. This was true for all of the residents of the nursing home, but especially for my great-grandmother. Her last name was Bearinger, so we all called her Nana Bear. She loved being called that, and the classic “teddy bear” became what we all remember her by. She was given at least one teddy bear on every special occasion, and had them everywhere throughout her room. She loved her teddy bears and now we hold on to them as reminders of her. Throughout my childhood, we did our best to visit my great-grandmother every week as a family. These visits not only helped my great-grandmother, but helped my family as a whole. These visits helped us all develop a closeness and unity during that time. We shared the burden, which made it not seem like a burden. We spent so much time in the nursing home in fact, that most of the significant events of my childhood were celebrated there. My annual piano recital was held there, as well as almost all of our family birthdays. We all loved her and created special bonds with her up until the day she died. She passed away at age 93; I was 12 years old.

Some might argue that Alzheimer’s disease takes away meaning in a person’s life. On the contrary, Alzheimer’s disease can bring meaning to people’s lives in a way that no one expects. It

is still very hard to not have known her when she was healthy because of the loving impact she had on the people around her. She was the oldest of six daughters raised during The Great Depression, married a navy officer who served in WWII, and raised two children. Later she raised my mom and uncle when my grandmother needed help as a single parent. Serving her family was how my great-grandmother lived her life. Alzheimer’s created an opportunity for our family to serve her in return.

My future plans include becoming an elementary special education teacher. As a teacher, I will ensure that my students learn the same things that I learned from having a family member with Alzheimer’s disease. I want to teach my students how to respect and care for elderly people, and put in the effort to show that they care. I want to take my students on field trips to let them experience the compassion that I was able to develop while taking care of my great-grandmother. I want to give children as many

opportunities as possible to become comfortable around people who have illnesses such as Alzheimer’s disease or dementia. For many children, as with me, it is scary to be around people with these types of illnesses because they are unpredictable and are not fully aware of their actions. However, through exposure and leading by example, I can

allow my students to become comfortable in unfamiliar and often frightening places.

The impact that Alzheimer’s disease had on my life through my great-grandmother’s journey is something that can never be replaced or recreated. It taught me to love unconditionally, to honor family bonds, and to do what is necessary even through scary situations. It means the absolute world to me that I was able to care for her and make her smile while she was alive. Despite her illness, I was able to create a special bond with my great-grandmother. Through coping with Alzheimer’s disease, I have learned how to truly value my life and the people in it. I have learned how necessary it is to cherish the time that we have left with our family and friends. I have also learned that nothing is pointless when it comes to helping people with Alzheimer’s disease. Even if they do not remember us, it means more to offer dignity and respect for their lives than to simply acknowledge or recognize them. A simple smile or holding a hand can mean the world to a person with Alzheimer’s disease, so we should always put in the extra effort to provide them even the smallest of comforts.



Brooke Serra was named second-runner up in AFA’s 2018 Teens for Alzheimer’s Awareness Scholarship Essay Contest and received a \$1,500 college scholarship. Brooke, who lives in Pittsburgh, Pennsylvania, will be studying early childhood and special education at the University of Pittsburgh this fall.

RECIPE FOR YOUR HEALTH

TZATZIKI



Tzatziki is a traditional Mediterranean dish that originates from Turkey and Greece. It's made from strained yogurt, also known as Greek yogurt and mixed with cucumbers, garlic, salt, olive oil and sometimes lemon juice. Herbs like dill, mint or parsley are added. It's served as a cold dip (sauce) with salads, meats, olives, bread and crackers. In Middle Eastern cuisine "mezze" platters are served with tzatziki alongside other salads and dips like hummus and baba ghanoush (cooked, mashed eggplant mixed with tahini and seasoning).

Greek yogurt is high in protein and calcium and low in calories. Cucumber adds fiber and a variety of vitamins and minerals. For an even more nutritious and delicious Mediterranean food experience, mix tzatziki with avocado. Then spread on spelt bread and top with chopped tomatoes and Kalamata olives.

This recipe takes ten minutes to make and has endless possibilities! Serve it with fish or poultry for a refreshing dipping sauce. Tzatziki mellows out spicy cuisines such as Indian. If you like sweet with savory, a fruit chutney pairs well. Otherwise, simply serve with toasted bread, crackers and fresh vegetable crudité.

RULES FOR MAKING TZATZIKI:

1. Use nonfat or low-fat Greek yogurt. Greek yogurt is already strained, which results in a creamy consistency for the spread.
2. Remove the seeds from the cucumber or use English cucumbers, sometimes labeled as seedless.
3. Fresh garlic, lemon and dill add superb flavor. However if you dislike any of these ingredients, just leave it out.
4. You can drizzle a small amount of fresh, cold-pressed extra-virgin olive oil on top before serving. Be mindful of the amount, because 1-tablespoon of oil adds 120 calories and 14 grams of fat.

Layne's Tzatziki Recipe (makes 3 cups)

INGREDIENTS (choose organic when available):

- 2 cups plain nonfat Greek yogurt
- 1 cup seedless cucumber, diced
- 1 ½ tablespoons fresh lemon juice (juice from ½ fresh lemon)
- 2 garlic cloves, pressed
- 1 tablespoon fresh dill, finely chopped
- 1 tablespoon fresh chives, finely chopped
- Sea salt to taste, optional

INSTRUCTIONS:

1. In a medium bowl, combine all ingredients.
2. For flavors to meld, chill in the fridge overnight.
3. Stir before serving.

This will stay fresh in the fridge for 3 to 4 days.

NUTRITION FACTS PER SERVING, based on 6-servings: 44 calories, 0 grams fat, 7.7 grams protein, 3.7 grams carbohydrate, 79 milligrams calcium.



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

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Iowa and Nevada College Students Join the Fight Against Alzheimer's Disease



Alzheimer's disease doesn't just impact those who have it; it affects their loved ones of all ages, including children and young adults. Many of these young people use their experiences with the disease as motivation to get involved in the fight against Alzheimer's. Right now, there are students across the country who are working to support families affected by Alzheimer's disease through the AFA on Campus program.

AFA on Campus encourages students to raise awareness about Alzheimer's disease, and its impact on everyone, at their high school or college. Each AFA on Campus chapter is founded by the students themselves. Oftentimes, students also organize, plan and promote their own fundraisers to help support AFA's programs, services and research efforts.

Students at Iowa State University organized a volleyball tournament this past winter to raise funds for AFA, as well as awareness about Alzheimer's disease. Over 100 players took part in the tournament and contributed hundreds of dollars toward the cause.

The tournament was organized by the Iowa State University Chapter of AFA on Campus. Chapter president Molly Norman was moved to get involved after watching her grandmother

live with Alzheimer's disease for many years, as well as through her work in a nursing home memory care unit. Other students also had personal ties to the disease.

This is not the chapter's first fundraising event. They previously organized a dodgeball tournament to raise charitable contributions for AFA.

Students at the University of Nevada-Reno held a fundraiser on campus on April 5th at Great Full Gardens Express. Students arranged to have 20 percent of each purchase donated to AFA, totaling over \$450.

The University of Nevada-Reno chapter is as new to the school as its founder, Kathryn Haran. An aspiring physician, Kathryn's experience watching her grandmother battle Alzheimer's disease led her to take an active role in raising awareness and encouraging others to do the same.

Iowa State University and the University of Nevada-Reno are just two of the many chapters across the country that are giving back, making a difference and developing the next generation of leaders in the fight against Alzheimer's. AFA is grateful to each and every one of them for their efforts.

Know someone who's interested in starting an Alzheimer's Foundation of America on Campus chapter at their high school or college? Contact the Alzheimer's Foundation of America at 866-232-8484.