

MIND MATTERS

INSIDE

- ◆ How clinical trials provide more benefit than just data
- ◆ A journey from professional nurse to full-time caregiver
- ◆ Helpful tips for caregivers
- ◆ Meet Oladele Owasoyo, PhD



SIU MEDICINE

DALE & DEBORAH SMITH CENTER
FOR ALZHEIMER'S RESEARCH
& TREATMENT

From the Director

Through the past two challenging years, the Smith Alzheimer's Center's mission to take Alzheimer's head on hasn't wavered. In this issue, you'll see a snapshot of how that has been accomplished through volunteer efforts in our clinical trials, persistence in our Beyond the Medical Center programs that offer camaraderie and hope, and through the consistent research in our labs. And we couldn't be more excited about the return of in-person events like our Brain Aging Conference!



Erin Hascup, PhD

We're also blessed to have incredible caregivers who want to help make sure those at an earlier stage of their journey have as many tools as possible at their disposal. I'm excited to introduce Ask a Caregiver, a column where caregivers wanting to learn more about how to help their loved ones can find useful day-to-day tips.

This issue features Sue Monteyne, who you might recognize from some of our Beyond the Medical Center programs, sharing some strategies that helped her and her husband navigate their journey with memory loss.

As always, thank you for reading and for your support!

GET INVOLVED

Would you like to receive our newsletter? Or maybe you're more interested in volunteering or enrolling in a clinical trial? How about all three?

Just let us know! Scan the QR code with your phone, or fill out our online form at siumed.org/alzconnect to let us know what you're interested in.

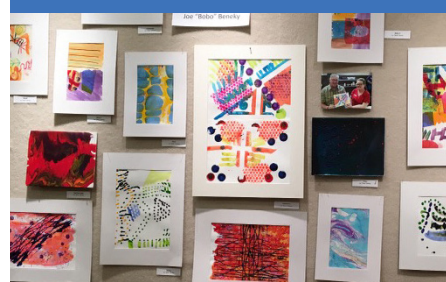


We'll be in touch!

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Staying active

Participating in activities we love adds meaning to our lives. For those with Alzheimer's, it can help connect them to memories or simply bring pleasure. But those with Alzheimer's can have trouble deciding what to do - organized activities can help alleviate stress.

Before you go...

Here are some tips:

- Plan outings when the person is at their best.
- Keep outings from becoming too long.
- Match the activity with their abilities.
- Choose activities fun for everyone.
- Make sure they feel accomplished.

Exercise

Take a walk together through a familiar area, use a stationary bike, toss a soft ball back and forth, or use stretching bands.

Gardening

Take care of indoor or outdoor plants, plant flowers and vegetables, talk about how much the plants are growing.

Favorite places

Those in the early stages of dementia may still enjoy a favorite park, restaurant, museum, shopping mall or theater. Keep going on these outings as long as you are comfortable.

Visiting with children

Play a simple board game, walk around the schoolyard, go to school events, or talk about fond memories from childhood.



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Having Alzheimer's stand trial

Springfield couple wants to help solve dementia through volunteering for clinical trials

As a teacher, Karen Perrero made plenty of lists to keep life and the classroom in order.

For around two decades, she taught at parochial schools as a science teacher, introducing young students to the world of science. But a few years ago, Karen started to feel a little off. She was becoming more uncertain in daily matters.

"I had this inkling there's something different in me," she said. "The way I couldn't remember things."

Her husband, Daren, noticed it too. The lists she used to organize life became more numerous and necessary. After a routine physical, Karen's physician recommended she take a cognitive assessment exam at the Smith Alzheimer's Center. She was diagnosed with dementia.



On the University of Illinois campus, college students Daren and Karen

Perrero fell in love with science and each other.

Karen's path to teaching science intersected with Daren's study of bioengineering, which eventually turned into working with the Illinois Emergency Management Agency and radioactive materials. They were coming at science from both sides, but with the same foundation.

"It was a match made in heaven," Karen said.

That background in science kicked into high gear a few years after



You want to be on the cutting edge of science? Here it is.

— Daren Perrero, on participating in a clinical trial

their son, Vince, was diagnosed with muscular dystrophy. The Perreros immediately peppered physicians with questions, asking what kind of treatments were available, what kind of cures, what options were out there to help extend life?

Vince unfortunately passed away in 2013 at the age of 22. "We sadly found out that technology and the related science as we knew it was not quite there yet," Daren said.

So when Karen was diagnosed with dementia, the Perreros had déjà vu, asking questions about a cure that didn't yet exist.

But they're determined to help find one. The Perreros have volunteered in two successive clinical trials, one consisting of taking a daily pill and one a daily injection, at the Smith Alzheimer's Center to help find better and more effective treatments.

Karen's father suffered from dementia as well, so they've seen its effects on multiple generations. Even if a cure isn't found in their lifetime, providing more data through a clinical trial offers a better chance for their daughters, Valerie and Abigail, and subsequent generations.

"Dr. (Tom) Ala always says this phrase that I didn't really fully appreciate until now," Daren said. "That is, 'Somebody is going to be the first person cured, and the first person to be cured will have been in a drug trial.'

"You want to be on the cutting edge of science? Here it is."

While a cure is the main goal, the Perreros have seen the added benefit from just enrolling. Instead of coming back every few months for an appointment, they have constant touchpoints with the Center. There are preset check-ins and opportunities to ask questions while updating the trial data.

"The biggest advantage to a drug trial is the immediacy, the interaction with someone who is as experienced and skilled as Dr. Ala and the support staff," Daren said.

"All of those interactions are great. You mention something changed or is different, they might say, 'Oh that's common,' or, 'That's extremely unusual. We should look into that further.' We're getting information that helps us on a day-to-day basis."

Between frequent visits to update the clinical trial, or coming back for a regular appointment, the sense of

warmth and friendliness has made visits that much more welcoming.

"The people we've dealt with at SIU – 'amazing' is a word that gets overused, but it certainly applies in this case," Daren said. "Their experience, knowledge, that information that they are constantly able to draw on and give out to you, that's fabulous."

"But I think what really makes it work is the personalities of the people. They tell a good joke and they laugh at my bad jokes. The staff and professionals here are absolutely amazing."

Want to get involved?

We'd love to tell you more. Reach out to learn about current trials and if you qualify.

All study-related drugs and assessments will be provided at no cost to the participant.

For more information, please contact: **217.545.9737** or email nsi_research@siumed.edu.

What goes into a clinical trial?

There's a long process before a drug is approved. The clinical trial process helps ensure its safety and efficacy.



PHASE I

- usually between 20-100 volunteers

Determines overall safety and the safest dose. This is the first time the drug is given to volunteers, who are usually healthy, although sometimes those with target disease are studied.



PHASE II

- usually a few hundred volunteers

Rigid, well-controlled studies. Subjects usually have the target disease and no further illness. Usually consists of double-blind studies using a placebo. Dose-range finding and establishing a min and max dose range effectiveness.



PHASE III

- often thousands of volunteers
- may extend years

Conducted if past phases have been successful. This study is expanded and controlled with types of patients the drug is expected to treat. Confirms long-term effectiveness.

PHASE IIIB

These are ongoing studies when a New Drug Application (NDA) is pending approval; purpose is to gather additional safety data.



PHASE IV

- may include thousands of people

After NDA approval, this phase helps determine more information about safety and efficacy.

Ask a Caregiver



Sue Monteyne is a former caregiver and current volunteer at the Smith Alzheimer's Center's Beyond the Medical Center programs. If you would like to submit a question, please email care@siumed.edu.

Q: I want to take my loved one to a favorite restaurant but make the process as enjoyable as possible. Any tips?

SUE: Sometimes restaurant menus can be overwhelming even for those without memory loss. I would look up the menu online and decide what we wanted before going to the restaurant (have a backup choice just in case).

We would also practice the choice while the server was gone so my husband could maintain his dignity and order his own meal.



Q: How should I answer repetitive questions?

SUE: I used to keep a white board on the end table next to his chair with the day of the week, date and events of that day. (ex. Wednesday, June 29, 2022. Go to doctor 10:00. Go to Art Express 1:00)

On the bottom half of the board, I would also include the next day. (ex. tomorrow, Stepping Up 12:00. Kids coming for dinner 6:00)

This helped considerably with repeated questions like, "What are we doing?" or "Where are we going?"



Q: Friends and family members seem unsure how to talk to my loved one now. What can I tell them to make it easier?

SUE: Friends and family should talk to your loved one just like they always have. Don't talk about them as if they weren't there. That just belittles them. Don't quiz them. Don't continually ask if they remember something and insist that they do. This will just cause the person with memory loss to feel frustrated and insecure.

Just be patient and understanding and believe what they say to be true. Because for some reason, they believe it is.



Q: How do I continue to live my life while helping my loved one?

SUE: Life goes on. Live it! Enjoy it! Make new memories. We continued to travel all over the world.

Airports can be challenging to navigate. I carried a card stating, "The person I am with has dementia. Sometimes he answers slowly, gets easily upset or seems confused. Your patience and kindness are appreciated. Thank you."

I translated this card into the languages of the countries we visited. I secretly showed it to ticket agents, security and customs. I also got permission (and was always kindly granted) to board the plane early to reduce the stress of your loved one feeling rushed.

Take advantage of family and/or accessible bathrooms so you can go together. Do not assume the person with memory loss will wait for you when exiting their bathroom. Most likely, they will go looking for you.

Travel with groups. You would be surprised how many people will gladly step up and help when made aware of the situation.

These tips are presented by an experienced caregiver. This information is not intended to replace treatment, care, or advice from a qualified professional. To make an appointment with the Smith Alzheimer's Center, call 217.545.8000.



EGG-CELENT COMPANY



Minds in Motion is an evidence-based program, designed for persons experiencing memory loss or dementia. The goal is to improve or maintain mental, physical and emotional well-being.

Often, the program themes its creative activities around an upcoming holiday or event. With shaving cream, neon food dye and a little artistry, participants dyed eggs in a recent class.

Photos by Ben Romang



Art in the right place



After finding comfort in the clinic, Benekys discovered outlet in 'Beyond' programs

There were few characters more colorful than Joe "Bobo" Beneky.

Just like the affectionate nickname might imply, he would do just about anything to elicit a laugh or a smile from anyone nearby. Dance with a silly hat? Not a problem. Sing at full strength? You could hear him before you saw him.

In fact, Bobo had his own "Where's Bobo?" book full of pictures of him hiding amid the scenery, waiting to give the reader a chuckle and smile when they finally saw him tucked behind a tree or in the corner of a room with a lampshade for a hat.

He bucked every stereotype for an accountant, and he was as charming as he was funny.

But after a corneal transplant surgery, it was obvious Bobo wasn't his usual self. He came out of the anesthesia aggressive, and his doctors came to the conclusion that a memory loss test was needed.

"I kind of knew there was something wrong before, but it hadn't been diagnosed," Nancy said. "Our primary doctor gave him one of those standard tests, and he maybe got half of it right. It was, 'Yeah, you need to see someone.'"

For Nancy, it was a rare time where she felt out of sorts in a clinical space. Through more than four decades prior, she saw almost every nook and cranny at St. John's Hospital as a nurse, including the last 18 years as an evening supervisor.



PHOTOS SUBMITTED BY NANCY BENEKY



Taking care of people was her life.

So when Bobo was diagnosed with frontotemporal dementia, her training kicked in. She was ready to be a caregiver. But it certainly

“
I felt like she understood the way I was feeling...

— Nancy Beneky,
on meeting Cindy Womack, DNP

helped having consistent care from the clinic and a friendly face in Cindy Womack, a certified nurse practitioner at the Smith Alzheimer's Center who saw Bobo at his first visit. Cindy brought the couple some peace of mind.

"Cindy always made me feel so comfortable and Bobo loved her," Nancy said. "Like I said, my husband

was a character, everybody loved Bobo.

"I felt like she understood the way I was feeling through her kindness, because she really knew what was going on."

Assistance also came from programs like Minds in Motion and Opening Minds through Art, which partners with the Springfield Art Association. Nancy said while he initially never wanted to go, Bobo's personality took over once he got there. He could belt out songs – Opening Minds through Art opens and closes with familiar songs to sing – and make people laugh. "He entertained all of them."

Like so many with dementia, experiences and memories fade quickly. But Nancy saw something take over at home as his colorful personality spilled over into a new fixation.

"Art, that connected. I bet I had 200 coloring books that he's done for the last year or two," she said. "And you could see the progression in those. How he did good in the beginning, but ... but he still liked to do it."

"He would color 8 hours a day," Holly Dahlquist, Nancy's daughter, added.

That love for art continued until Bobo passed away in October 2021. He would spend hours on artwork with a professional caregiver, a move Nancy put off until she realized that the mood swings and physical demands were too much, even with help from her children.

"People rely on other people. She did it all on her own until she couldn't do it," Holly said.

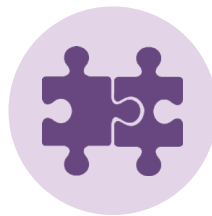
Bobo's passing was rather sudden. For Nancy, who fell in love with Bobo from their first date – at junior year prom more than 60 years ago – it's been an understandably tough time. But she credits conversations with Cindy and Ann Jirmasek, a gerontology specialist, for helping navigate her grief and loss of Bobo.

"I would suggest SIU for anybody."

CONNECT & FIND RESPITE

Our **Beyond the Medical Center** programs focus on ways to improve the quality of life for not only those with memory loss but those caring for them as well.

Each session provides a chance for caregivers to connect with other caregivers who understand the unique challenges they face. But it can also be an opportunity to provide respite for caregivers, as staff and volunteers provide support and care for those with memory loss.



MINDS IN MOTION | TUESDAY

First and third Tuesday of month

Use all five senses to improve or maintain mental, physical and emotional well-being.



ART EXPRESS | WEDNESDAY

Every week

Express creativity without needing memory or communication skills.



STEPPING UP | FRIDAY

Every week

Fitness and fun with music and movement, focusing on strength, balance, endurance and flexibility



MUSIC & MEMORY | ON YOUR TIME

Stimulate deep emotional recall through familiar music from their past.

To register for a program, or to learn more information:

☎ 217.545.7204

✉ care@siumed.edu

🌐 siumed.org/alzheimers-center-programs



MEET A RESEARCHER

OLADELE OWASOYO

Oladele (Dickson) Owasoyo, PhD, is the newest addition to the research team in the Hascup Labs, coming to the Smith Alzheimer's Center at SIU Medicine after receiving his PhD in biology with focus on physiology at University of Benin in Nigeria, and then most recently a Masters in biology at Western Illinois University.

Q: What sparked your curiosity in neuroscience?

A: Right from my childhood, I have always loved to understand the delicate but complex and multi-functional nature of the human brain. Also, reading and hearing about neuroscience research, coupled with wondering about how surgeries are done on the brain despite its delicate nature ignited me into learning more about the brain, and thereby learning more about neuroscience.

I have also developed over the years love for those with neurodegenerative diseases and passion for its treatment and cure, hence, that has really encouraged me to further study

neuroscience in order to figure out how I can contribute in the quest for their successful treatment and cure.

Q: What excites you about the future of neuroscience?

A: The use of stem cells to treat or cure neurodegenerative diseases such as Alzheimer's. Stem cells are one of the recent medical approaches used as a therapy to treat or cure diseases. It has the potential to be used to regenerate new cells and tissues in human brain or body which in the future may form a basis for treatment or permanent cure for Alzheimer's disease.

With the help of funding from the National Institutes of Health

and generous donations, and the effort of the brilliant medical professionals and scientists at SIU Medicine working in harmony to find treatment and cure to Alzheimer's disease, coupled with the promising results we are currently seeing, I am certain we are making great strides to determine early biomarkers and novel treatments that have the potential to decrease the occurrence of Alzheimer's disease in the U.S.

Q: What's your favorite piece of advice you've received?

A: Always set your goals and work towards achieving them. You may get tired on the way, but you just need to persevere and be encouraged.



MIND diet offers healthy option



Charlyn Ware, RD

While so much of dementia is unknown, one thing does seem to be clear: A healthy diet can make a difference. But what does that healthy diet look like?

The MIND diet is a hybrid of the Mediterranean and DASH (Dietary Approaches to Stop Hypertension). Overall, the MIND diet emphasizes natural plant-based foods and limited intakes of animal foods and saturated fats. However, it specifies adding berries and green leafy vegetables.

According to Rush University researchers, who studied 900 older Americans over a five-year period, those that followed the MIND diet lowered their Alzheimer's risk by 53 percent.

Here's a recipe that fits into the MIND diet plan:

Spinach strawberry salad | Serves 4 (about 2 cups each)

INGREDIENTS

Easy Herb Vinaigrette

- 9 tbsp white wine vinegar
- 1 ½ tbsp wildflower honey
- ½ tsp fine sea salt
- ¾ cup canola oil
- 4 tbsp chopped fresh basil
- 3 tbsp minced fresh chives

Salad

- 1 ½ cups quartered strawberries
- ¼ cup Easy Herb Vinaigrette
- 2 tbsp finely chopped fresh mint
- 1 (6 oz.) package fresh baby spinach
- 2 tbsp sliced almonds, toasted
- ¼ tsp freshly ground black pepper

DIRECTIONS

1. Combine the white wine vinegar, honey and sea salt in a medium bowl
2. Slowly whisk in oil until combined.
3. Stir in basil and chives.
4. Combine strawberries, ¼ cup vinaigrette, mint and spinach in a large bowl; toss gently to coat.
5. Sprinkle with almonds and pepper; serve immediately.
6. Store remaining vinaigrette, covered, in refrigerator for up to 5 days.

NOTE: Can also add avocado, goat cheese or grilled chicken.

Become a Dementia Friend

Helping our community recognize and understand Alzheimer's and dementia

Imagine walking into a restaurant and the server understands why your partner is taking longer ordering his/her meal, or perhaps a neighbor at the park recognizes someone who is lost.

All too often, persons living with or at risk for dementia feel alone and unheard. Dementia Friends Illinois works to reverse that narrative.



Communities big and small can see the value in making their communities more dementia friendly. By helping everyone in a community – from each person to institutions of all size – understand what dementia is and how it affects people can make a difference for people touched by dementia.

This fits within the goal creating dementia-friendly communities that are informed, safe and respectful of individuals, caregivers, and their families to provide supportive options that foster quality of life.

To learn how to become a Dementia Friend, visit dementiafriendsusa.org.



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Help us take Alzheimer's head on.

Whether it's our clinical care, research or programs, your donation supports our vision of better health for all.

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Thank you.

