

Alzheimer's Update

Community activism through research participation

A community activist and long-term participant of the AADAPt study reflects upon her experience together with her daughter

Community has been an important part of Leona Smith's life ever since she moved to Oregon 70 years ago. Community engagement has also been a driving force of the African American Dementia and Aging Project (AADAPt), and one of the main reasons Leona enrolled in the study two decades ago. A former special education teacher, NAACP and Urban League volunteer, and long-term active parishioner at Maranatha Church of God in NE Portland, Leona volunteered for the study not only to support research and the African American community, but also to meet new and old friends.

"She really loved the coming together of the community," says her daughter and caregiver Debra Wallace. "She also wanted to help a study of the African American population, since there's so little research that has been done in our community."



Debra Wallace and her mother Leona Smith at OHSU following one of the clinic visits that are a part of the AADAPt study at the Layton Center.

Coordinated by the Layton Aging and Alzheimer's Disease Center at OHSU, the study follows African American and Black participants in Oregon year after year. Research staff assess their cognitive and physical health and ask questions about their medical history during an annual clinic visit.

Most participants, 55 or older, have been involved for a decade or more. Data from the study furthers research about brain health, memory and aging.

A key component of the study has been the annual appreciation brunches, where Leona and her

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Making sense of supplements and alternative treatments

Oftentimes, it can be difficult to distinguish how and if nutritional supplements, lifestyle protocols and dietary plans can impact brain health. Lynne Shinto, Ph.D., a naturopath of 18 years with the Center for Women's Health at OHSU and a frequent research collaborator with the Layton Aging and Alzheimer's Disease Center, as well as Aimee Pierce, MD, Director of Clinical Care and Therapeutics at the Layton Center, regularly see patients who ask for guidance during their journeys with cognitive health. Here they share answers to some commonly asked questions.

“If you're going to make a change, hone it down to what seems the most relatable and doable,” says Dr. Shinto. “Quality of life matters.”



Lynne Shinto, PhD, Naturopath with the Center for Women's Health at OHSU .

Should I be taking dietary supplements?

According to Dr. Shinto, there isn't any clinical trial evidence that dietary supplements show effectiveness in decreasing dementia risk or slowing progression. Supplements like ginkgo, turmeric, or fish oil are not harmful, but neither Dr. Shinto nor Dr. Pierce recommend them. If you do decide to take supplements, make sure your medical provider is informed, as some supplements might have



Aimee Pierce, MD, Director of Clinical Care and Therapeutics at the Layton Center at OHSU.

interactions with prescriptions. “If I have a patient who is taking a supplement, I tell them, ‘Try it for a set period of time.’ If you notice that you're feeling better, then good. If not, why continue taking it?” says Dr. Pierce.

What about lifestyle protocols, such as the Bredesen protocol?

Lifestyle protocols are often framed in a scientific fashion. They often require extensive lab work, MRIs, or rigid dietary

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friends could celebrate each other, socialize and learn about the latest in brain health research.

“I liked learning about something that I was not aware of before. That’s a part I enjoy,” says Leona.

Debra attended the brunches with her mother. “Every year we’d meet someone new at our table. Before she was diagnosed with dementia, she was very outgoing and would work the room, embracing friends she hadn’t seen in a long time.”

Before she retired, Leona was a special education instructor and community agent at Jefferson High School. Former students still approach her, thanking her for the impact she had on their lives. Members of her church congregation come up to hug her when she attends services on Sundays. Community activism is still important to her. Both Leona and her daughter plan on creating a new ministry at their church called “Seniors Matter Too” to counteract ageism, prepare older adults for the future, provide a space to share advice and motivate others to get involved with research.

“Commonality means being of help to somebody else, be it at a nursing home, your church community, or volunteering with a research study. People need to be involved,” says Debra. “Volunteer what you can bring to the table.”

Debra has been her mother’s caregiver for the past two decades and has supported her through the early stages of her diagnosis. Observing her mother’s activism



Before joining the AADAPt study, Leona was a special education instructor.

and resilience over the years, as well as her participation in AADAPt, has inspired her to pursue her PhD in gerontology, start a clothing line for older women using her forty years of career expertise in the fashion industry, and motivate others like her to stay engaged in their parents’ lives. Watching her mother be part of AADAPt made her realize that volunteering for a study can inspire others to not only join a study, but to find other ways to benefit their communities.

Being in a study is for yourself, yes, but it also impacts more people. It mushrooms to other communities,” says Debra. “Researchers can gain a lot of information from our community. We haven’t had the research emphasis that other communities have had. Our community is a goldmine for

“Our community is a goldmine for research,” says Wallace.”

research.”

Leona continues to participate in the annual assessments, keep in touch with fellow participants, and attend Maranatha Church, one of the largest congregations in the African American community in Portland. She hopes more Black Oregonians and others get involved in research and make differences in their communities.

“I know my information from the study is going to help others,” says Leona. “I want to help others who are in a situation similar to mine.”

Learn more about our research by contacting our team at 503-494-7647 or emailing adresearch@ohsu.edu.

We have information about:

- The AADAPt Study
- Aging and dementia research
- Family caregiver research and support

When caregivers become friends

Sometimes you realize that another person's journey is as complex and vivid as your own. When three caregivers enrolled in the virtual TeleSTELLA study last fall, they didn't expect to realize that their individual caregiving experiences were in fact aligned in many ways.

Amy, a former social worker, Edna, a former college guidance counselor, and Georgia, who worked in adventure travel, got the chance to reflect about their struggles and triumphs during their journey of caring for their partners who were diagnosed with dementia.

As their friendship grew, they learned a lot of lessons from each other, such as:

- **Having compassion for yourself:** As Amy mentioned "No blame, no shame. It's important to have compassion for yourself, especially in the context of interacting with a brain that works in a different way than you've ever known it to work before."
- **Being adaptable and flexible:** As Edna mentioned, it's important to be flexible to different situations and to stop and reflect about an issue before trying to resolve it. She says "My mantra right now is - each day is a new adventure."
- **Having a supportive network:** All three caregivers mentioned how validating it felt knowing that they were not alone in their experiences. They were able to share ideas, tips, and resources, such as what types of tieless elastic shoelaces worked best. As Georgia said, "We gave each other support and advice. We knew what it's like



Edna and Georgia got the chance to meet up after the Tele-STELLA study concluded.

to walk in each other's footsteps as we dealt with this cruel disease."

Though they are all in a different place with the disease and though they do not reside in the same cities, Amy, Edna and Georgia know that they'll continue to share advice, reminisce, and keep in touch. They all recommend joining a caregiver-focused research study or educational support group, knowing how many unexpected benefits it brought the three of them.

Support is available—call us at 503-494-7467 to learn about our caregiver programs and research. The Multnomah County Family Caregiver Support Program - 503-988-3646 - and The Alzheimer's Association, are sources of support, 800-272-3900. Oregon Care Partners offers free caregiver training online: oregoncarepartners.com (on-line and in-person), 1-800-930-6851.

The Tele-STELLA Study is looking for caregivers. If you would like to know more about it, visit our website: <https://www.ohsu.edu/oregon-center-for-aging-and-technology/tele-stella-study>, or call us at 503-701-8566.

Sherril Gelmon, Professor at the OHSU-PSU School of Public Health, shares why she decided to give to the Layton Center

What can you do with your lived experience and expertise? For Sherril Gelmon, being a health services researcher, a research study partner, and a care partner for many years inspired her to donate to the Layton Aging and Alzheimer's Disease Center at OHSU and motivate her friend and family network to do the same. So far, they've donated nearly \$20,000.

"I've reflected a lot on my experiences," says Sherril. "How can I harvest my lived experience and direct my energies and intellectual curiosity to do something positive?"

Sherril is a Professor at the OHSU-PSU School of Public Health. As a health services researcher, she studies and teaches about health systems policy and delivery of health services. Working in academia, Sherril knows how much research is dependent on grant funding and philanthropy.

"Funding through philanthropy gives researchers more flexibility to do things that may not be able to with grant funding alone," says Sherril.

Sherril was first introduced

to the Layton Center when her husband, Phil Kreitner, became a patient and research participant there in 2010. Over the years Phil participated in multiple studies, including clinical trials and some technology-related studies. Sherril was his study partner when one was needed, as well as his care partner throughout his 11-year journey with Alzheimer's disease.

On Phil's 75th birthday in 2014, Sherril designated the Layton Center for gifts from friends and family. When Phil passed away in August 2021, she again asked those who wished to celebrate him to donate. She has also given on her own over the years.

"I'm hoping to bring more focus to care partners," says Sherril. "I value the clinical services we received and also learned there were many other social supports I needed to identify to support us as we navigated life with Alzheimer's."

Sherril hopes others give to the Center as well, so it can continue its mission of advancing care and treatment of Alzheimer's. She has recently redirected her own research program and received a grant from



Sherril Gelmon and her late husband Phil Kreitner enjoyed hiking together

the PSU Institute on Aging to collaboratively work together with the Layton Center's Dr. Walt Dawson and Dr. Allison Lindauer to expand its resources for care partners of people living with dementia."

"I wanted to bring together my lived experiences and my deep appreciation for the Layton Center to help do something new," says Sherril.

Help us find promising treatments for Alzheimer's disease by making a donation. OHSU Foundation exists to secure private philanthropic support to advance OHSU's vital missions, and to invest and manage gifts responsibly to honor donors' wishes.

To make a donation to support the OHSU Layton Center, please call OHSU Foundation at 503-228-1730 or visit <https://give.ohsufoundation.org/>.

Helping you find the right study

Natasha Spoden, M.S.

Research Associate, Layton Aging and Alzheimer's Disease Center

To learn more about our current research opportunities, call Natasha at 503-494-7647 or email at adresearch@ohsu.edu



Did you know the OHSU Layton Center has a research navigator? Finding the right study can be daunting for individuals and their families. My job is to make that easier.

How did I land this role? I left a 13-year career in Organic Produce in Eugene, Oregon to study aging at the University of Utah, graduating with a Master's of Science in Gerontology in 2013. After being at OHSU for four years, the Layton Center created the Research Navigator position, recognizing we needed someone who could answer the many questions people have about research, dementia support and education.

I am sure some of you have questions about being in research and what the next step would be. One thing people often don't realize is that you don't need to be a patient at OHSU to be part of research or attend our support groups and educational opportunities.

Our range of studies includes:

- **Clinical trials:** Testing ways to treat, detect and prevent

memory loss and dementia

- **Educational online programs:** Learning how to care for someone with dementia and providing feedback about the program
- **Online surveys:** Sharing your opinions about healthcare and technology
- **Longitudinal:** Allowing researchers to collect data about you (through surveys and observations) over an extended period of time to gain insight into the aging process

As Research Navigator, I work with the community, our researchers, providers and local, state and national teams to increase awareness about research opportunities. I can help you if you are interested in talking about what participating in research is like. I can also connect you with our newsletters and listservs so you hear about educational opportunities. We have experts – invested in topics from dementia prevention to caregiving to Lewy Body Dementia – that study

and write about their interests and stay connected with the community.

Our research registry is a good place to let us know you are interested in research participation. To sign up, please visit our website www.alzactnow.org.

My favorite part of the job is connecting people to a study or resource that they may find helpful.

Being involved in a study is a good way to connect with our team of dementia experts, avoid isolation and contribute to your community. I am grateful for all those who have participated in research and have supported the scientific process.

While I have never participated in a study, I am now so dedicated to research that my body will go to OHSU's body donation program when I die – I want to pay it forward after my last breath.

STAFF CORNER

plans. Though people may find some aspects of it to be helpful, there are many components involved, and it can be complicated and expensive.

“The way that it’s done, is that you’re supposed to change everything at once and that’s overwhelming. I think the main thing people come to me with is feeling stressed out,” says Dr. Shinto. “And stress is not good for your brain.”

According to Dr. Pierce, though a protocol may seem scientific, it is not a clinical trial or research study. In scientific research, a participant should not be paying to participate and should not be paying the investigators.

Most clinical trials involve a placebo and are double blind, since that is the standard for determining if an intervention or a medicine is really helpful. If everyone is getting the same treatment and if everyone is paying for it, that’s a red flag.

How can I avoid misinformation?

Part of the provider’s role, according to Dr. Pierce, is to answer questions about approaches that a patient may have. If you’ve read something online, you can bring it up during your next appointment.

It’s always a good idea to check your sources and to find reputable ones, like the Alzheimer’s Association. Many hospitals, including OHSU, have information about health



conditions on their websites.

How can I go about supporting my cognitive health?

As a naturopath, Dr. Shinto asks patients about their diet, physical activity, movement, mood and coping, stress levels and social engagement.

Using that as a foundation, she analyzes what areas can be strengthened in a realistic and sustainable way. Instead of embarking on a drastic change, it’s better to reinforce the good things already happening and then ask about smaller steps. If you enjoy going on longer walks,

continue building upon that habit. Instead of switching to a new diet overnight, try eating a little less processed sugar.

“When you’re 75 years or older, quality of life matters,” says Dr. Shinto. “If you’re going to make a change, hone it down to what seems the most relevant, relatable, and doable. People are not going to sustain changes if they’re overwhelmed.”

How can I support future research about dementia?

According to Dr. Pierce, the number one risk factor for dementia is aging and we are all potentially at risk as we get older. When there is a disease that does not have a cure, participating in a clinical trial makes sense, both for any potential personal benefit and to advance science. Research studies need people from all backgrounds to volunteer.

“In that sense, everyone is a candidate for volunteering for a prevention research study,” says Dr. Pierce.

“Everyone is a candidate for volunteering for a prevention research study,” says Dr. Aimee Pierce.”



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The C. Rex and Ruth H. Layton Aging and Alzheimer's Disease Center

The Layton Aging and Alzheimer's Disease Center is one of the 33 NIA Alzheimer's Disease Centers in the U.S. and the only one of its kind in Oregon. Our center is recognized as a national leader in dementia care and research, and is committed to serving the needs of people throughout the Northwest.

The Layton Center is a part of the OHSU Brain Institute (OBI). OBI is a national leader in neuroscience patient care, research and education.

For more information, contact the Layton Center at 503-494-6976. To subscribe to our website www.ohsu.edu/alzheimers or call 503-494-6370

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The C. Rex and Ruth H. Layton Aging and Alzheimer's Disease Center is dedicated to the study and treatment of Alzheimer's disease and other dementias.

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