

Alzheimer's Update

Stepping up for Alzheimer's research

Family history and professional experiences encouraged an Oregonian to volunteer for the AHEAD clinical trial

Volunteering for the AHEAD clinical trial has given Jennifer Weiss more than one way to give back to her community. Jennifer works with older adults and their families in The Dalles, Oregon, as part of her job with the Department of Human Services. Participating in the nationwide clinical trial has not only expanded her knowledge of dementia, but it has also shown her more ways to help the people she works with.

"I see the effects cognitive decline, dementia and Alzheimer's on the individuals and their families on a daily basis," says Jennifer. "It's a horrible disease process."

Once a month she travels to the Layton Aging and Alzheimer's Disease Center at OHSU to receive infusions of a new investigational treatment. The AHEAD clinical trial is testing whether this treatment, the antibody lecanemab, can prevent Alzheimer's disease before symptoms develop. Brain



Jennifer has been volunteering for the AHEAD clinical trial at OHSU.

changes related to Alzheimer's can begin up to twenty years before a person notices any cognitive symptoms.

The study is testing people as young as 55 who have a higher risk of developing symptoms of Alzheimer's later in life.



Jennifer's mother, Dolores "Dee" Weiss.

Jennifer's mother had Alzheimer's. Her grandfather and great-grandfather had dementia as well.

"I don't have a lot of money to put towards a cause. What I do have, and what I think is more valuable, are my genetics," says Jennifer.

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Inspiring young minds to pursue research

Funded by the National Institutes of Health, BUILD EXITO is a three-year program at Portland State University (PSU) designed to train undergraduate students in health science research. This program identifies underrepresented students early in their college careers and engages them in finding solutions to today's major health problems. OHSU serves as a research-intensive partner, providing crucial support, guidance and expertise for EXITO scholars.

Currently, there is one EXITO scholar at the Layton Center, Remonda Hanna. She shares insights about her experience.



Remonda Hanna, EXITO scholar .

As a Data Science major at PSU, I've taken many math, statistics and programming courses without actually knowing what a data scientist does. In 2021, I joined the BUILD EXITO program because I knew it would give me a better understanding of how to apply the degree I'm working towards. I'll be graduating from PSU in June. 2023 is my last year as an EXITO scholar.

I've always been curious about how different parts of the brain work, especially when it comes to Alzheimer's disease. When I got the opportunity to join a lab at ORCATECH (Oregon Center for Aging & Technology), I immediately accepted. It was something I couldn't pass up. At ORCATECH I worked with my mentor **Michael AuYeung, PhD.**, and helped him aggregate data from two of his



Michael AuYeung, PhD, Remonda's mentor

research projects, the MODERATE (Monitoring Dementia-Related Agitation Using Technology Evaluation) study and the ADA (Monitoring Apathy, Depression and Anxiety Using Technology Evaluation) study.

During my time at ORCATECH I improved my programming skills while working with real life data and learned how to properly display my findings.

After graduating, I'll search for an internship in the data science field that'll help me grow in my career. EXITO has many perks but what I've enjoyed the most is the continuous support from everyone in the program. Whatever I needed help with, whether it was personal or school or research related, EXITO was always there.

“If the research team can learn something from my genetics, then I’ve done something good.”

During each visit, she gets an infusion, but does not know if she is receiving the drug or a placebo. Neither Jennifer nor the study team, led by Aimee Pierce, MD know whether participants receive lecanemab or a placebo until after the study concludes in four years. Sponsored by the National Institutes of Health (NIH) and Eisai Inc., the clinical trial is recruiting 1,400 people across the United States and the world.

Her mother passed away in 2003, ten years after she first started showing symptoms.

“I felt like we lost our mom bit by bit,” says Jennifer. “She was a strong woman, a social and curious person, so it was a painful and frightening process for her to go through as well.”

Jennifer has children and grandchildren. When she thinks about her family’s history with the disease, she’s thinking about them too.

“I don’t want to put my family through that grief,” she says.

During her monthly visits, she knits, reads, and chats with the nurses. She’s learned a lot about brain health and genetics through her involvement in the study.

In addition to monthly infusions, study participants also undergo cognitive testing as well as brain scans that capture images of amyloid and tau. The clinical trial

team will compare the scans to the results of the cognitive tests, which might help them better understand how Alzheimer’s disease begins to develop.

Those cognitive tests are the same ones that she gives her clients at work, although it is a new learning experience being on the receiving end. The knowledge and insights she has gained from the study have weaved their way into conversations with coworkers and clients.

“Having been in this study, and having gone through what I did with my mother, I can offer insights and help people better understand what their family members might be going through,” says Jennifer.”

A year after enrolling into the study, the experience has given her peace of mind. She encourages others to volunteer, so that researchers can have a better chance at detecting and treating Alzheimer’s earlier.

“What I do have are my genetics,” says Jennifer Weiss. “If the AHEAD clinical trial team can learn something from my genetics, then I’ve done something good.”



Jennifer - on the left, in green - with her mother - in yellow - her grandfather, brother and sister on a trip to the Oregon coast.

“It’s so important for people to step up and do what they can to better our society and contribute to research,” says Jennifer. “Without people willing to step up, we really can’t treat Alzheimer’s.”

Learn more about research at the OHSU Layton Aging and Alzheimer’s Disease Center by contacting our team at 503-494-7647 or emailing adresearch@ohsu.edu.

We have information about:

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

Tackling caregiving responsibilities as a family

Sisters share what they learned from caring for their mother

Sisters Gahlana Maxey Easterly and Donna Maxey cared for their mother, Johnnie Maxey, for twenty-four years before she passed away at the age of 101.

Both of their parents were enrolled in the AADAPt (African American Dementia and Aging Project) program at the Layton Aging and Alzheimer's Disease Center at OHSU.

During those twenty-four years, they juggled their careers, aspirations, and personal lives, in addition to making sure their mother lived a healthy and happy life.

They share some advice about caregiving they learned over the years.

- **Don't have unreasonable expectations about teamwork:** Prior sibling dynamics, birth order, personality strengths, and external responsibilities can all play a role in how siblings approach caregiving as a team. Both sisters acknowledge that every sibling should participate, but balance is difficult to achieve. "Be aware that everybody is not going to be doing things equally," says Gahlana. She adds that it is important to prioritize according to siblings' strengths and situations, so that you can do what you can, when you can. "There isn't a perfect way to care for one's parents," she says.
- **Create moments of joy:** Both sisters



Mrs. Johnnie Maxey, on the left, celebrates her 101st birthday in August 2020 with her daughter Donna Maxey, on the right.

organized moments of joy, for their mother and for themselves. Gahlana worked at a florist distribution center and would bring flowers that would otherwise be discarded, back to her parents' home. She would arrange bouquets in every room. "It brought my mother joy. It's something I needed to do to keep my sanity," she says. Johnnie was a bedrock of the community, who helped run their family's grocery store in the past, so they would host large birthday parties for her. For her 100th, 300 people attended a party at Dawson Park. "We went all out for mom," says Donna.

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Leaving a lasting legacy

A former caregiver shares why she decided to donate her estate

Anita Perez knows the devastating effect that dementia has on families. Watching her late father live with the disease took a toll on her. Her friends and neighbors have all cared for someone who had Alzheimer's disease or a related dementia.

"It's a silent disease that affects everybody," says Anita. "My father was living in an assisted living facility, but it was still very mentally exhausting dealing with his diagnosis."

After living on the Northern Oregon coast for twenty years, Anita moved back to Portland and started searching for a way to support those impacted by the disease.

Although she had no prior connection to the OHSU Layton

Center, she learned about its research, clinical care, and community support programs.

With support from the OHSU Foundation, she filled out the paperwork and decided to include the Layton Center in her estate plans.

"Four years ago, two of my close family members passed away unexpectedly from heart disease, so you'd think that's where my money would go," says Anita. "But Alzheimer's is on the top of my list. I've seen it impact so many people over the years, including so many families and caregivers."

While living in Oceanside, a coastal community near Tillamook, a friend talked her into becoming a real estate appraiser. She worked in that field for several years, while also taking care of her father, who resided in an assisted living facility nearby. Her late husband was her 'support group' at the time.

That professional experience shaped her knowledge of the real estate market and later on, led her to donate her entire



Anita Perez decided to donate her estate to the OHSU Layton Center.

estate to the Layton Center. That long-lasting investment will contribute to future clinical trials, funding for caregiver resources, and other programs that support patients and families.

"My biggest interest is to support more research. Hopefully one day that will lead to a cure," says Anita.

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/>.

"My biggest interest is to support more research," says Anita. "Hopefully one day that'll lead to a cure."

Charles Fennell, B.S.

Community Outreach Specialist,
Layton Aging and Alzheimer's Disease Center



Charles Fennell comes to the Layton Aging & Alzheimer's Disease Center at OHSU from Charlotte, North Carolina. Since August of 2022, he has served as the Layton Center's Community Outreach Specialist. In this position, Charles engages community members, provides education to groups about dementia, treatment, and informs people about healthy aging research opportunities.

He is hoping to meet with people from community groups, churches, professional organizations, as well as local leaders, to promote research engagement with groups historically underrepresented in Alzheimer's disease research, particularly Oregon's African American community. He has always maintained an interest in neuroscience but is motivated primarily by his passion of working at the intersection of science and community.

Charles holds a Bachelor of Science in Psychology with a concentration in Natural Science and a minor in

Statistics awarded by Appalachian State University. He is no stranger to organizing efforts to combat Alzheimer's disease.

In high school, Charles' mother worked as the Director of Finance and Operations for the Western Carolina chapter of the Alzheimer's Association. Charles and his sisters would often support their mother at many "Walk to End Alzheimer's" events by distributing food and drink to walkers, assisting with registration, and helping set up and clean up each event. Many families affected with Alzheimer's and related dementias would share their stories and testify to the horrors of the disease.

Volunteering at these events inspired Charles to organize his own 5K Alzheimer's Walk for Awareness in a region of North Carolina that did not have any prior Alzheimer's disease fundraising events or opportunities. During the two years prior to the pandemic, Charles and the Appalachian Neuroscience Organization raised over \$3,500 to donate to the

Alzheimer's Association.

He learned a lot about community outreach by going door to door in the town of Boone, North Carolina looking for local businesses willing to sponsor his walk with advertisements, food, or even items to auction off.

He hopes to build upon those early networking and organizing skills to make research more accessible to communities of color.

The job has many rewards, but Charles' favorite is making lasting connections with organizations. He enjoys how receptive the community has been to receiving information about dementia and how supportive organizations have been to share that information with the community.

Charles is excited to continue to support the Layton Center's great outreach work.

STAFF CORNER

- **Have important conversations ahead of time:** Donna, who was juggling graduate school and work at the time, emphasizes that communication is key. Conversations about caregiving ideally should happen before parents need that support. Siblings should not only talk about logistics, but about possible relationship changes – between siblings and between children and their parents - that come with caregiving. Gahlana adds “We often don’t think about it until it’s honestly too late.”

- **Acknowledge the challenges but find ways to relieve stress:** Both sisters mention that financial, physical, social, and emotional challenges often arise during the caregiving process. Situations like remodeling a home to better suit your aging parents, managing their meals, and carrying them and helping them get dressed take a toll on your body and psyche. Donna acknowledges that it was hard to turn the caregiving persona “off”, even when she went on vacation. “Your life can become wrapped around that person,” she says. Emotional actions, like trying to cheer your parent up, are more subtly challenging. Gahlana adds,



Mrs. Johnnie Maxey, on the left, with her daughter, Gahlana Maxey Easterly, on the right. Gahlana and her sister Donna took care of their mother for 24 years.

“It was challenging to become the parent to my parent.” Both of them say that finding ways to de-stress is important, as is trying to set boundaries. They both like to walk, so forming a walking team and participating in an annual walking relay, was their way to relax. They were - and still are - involved in city civic life.

Though those twenty-four years had many trials and tribulations, many moments of positivity wove their way in. “We were phenomenal,” says Donna. “It’s amazing that we’ve done as well as we have for as long as we have.”

Both now retired, Donna and Gahlana are proud of their efforts taking care of their father, and for a longer period of time, their mother. “We made sure our mom was rewarded for all the years she sacrificed for us,” says Gahlana. “She needed to know she

was protected and heard. That’s ultimately what everyone on Earth wants.”

If you’d like to learn more about the AADAPT program or our other research opportunities or caregiver programs, please call us at 503-494-7467.

The Multnomah County Family Caregiver Support Program - 503-988-3646 - and The Alzheimer’s Association are additional sources of support, 1-800-272-3900. Oregon Care Partners offers free caregiver training online as well: oregoncarepartners.com (on-line and in-person), 1-800-930-6851.

Two of our studies, the SHARP-CG study and the Tele-STELLA study, are looking for caregivers to volunteer as research participants.

If you would like to learn more, please contact us at adresearch@ohsu.edu or 503-701-8566.



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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 go 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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