

Alzheimer's Update

Caring for the caregivers

A new initiative backed by OHSU will explore methods to improve the health and well-being of Alzheimer's caregivers and their family members, funded by a five-year award from the National Institute on Aging, a division of the National Institutes of Health.

Alzheimer's disease affects millions of people around the world, so it's no wonder that research focuses on finding new ways to treat or prevent the onset of the disease in the future. Much less attention has been paid

to the partners and spouses who are providing care right now.

That's about to change.

A new initiative at OHSU – backed by a five-year award from the National Institute on Aging, a

division of the National Institutes of Health – will explore methods to improve the health and welfare of caregivers. This new Roybal Center will design and test interventions to help people improve the care of their family members while maintaining their own health and well-being.

“The level of stress for these family members is extremely high,” said **Allison Lindauer, Ph.D., N.P.**, an assistant professor of neurology in the OHSU School of Medicine. “You’re experiencing a form of chronic grief every time you lose a little more of your family member with dementia.”

The award is expected to total \$3.8 million over the next five years.

The Alzheimer's Association estimates the cost of unpaid care for people with Alzheimer's disease and dementia will rise to \$1.1 trillion in today's dollars by the year 2050. At the same time, caregivers themselves pay an even steeper cost.



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New clinical trial targets amyloid “protofibrils”

Amyloid beta (A β) is a protein normally produced in the brain that can build up in older people, forming amyloid plaque deposits. Amyloid beta can exist in several forms including oligomers, protofibrils, and fibrils, a key component of plaques. Amyloid protofibrils and oligomers are clumps of amyloid proteins. Protofibrils and oligomers differ from plaques because they are smaller, they exist in a fluid solution rather than a solid, and they may be more toxic to brain cells. A new clinical trial at OHSU called Clarity AD will test if a novel investigational antibody in development, BAN2401, which

selectively targets aggregated amyloid beta, including oligomers, protofibrils, and to a lesser extent, fibrils, may slow the progression of Alzheimer’s Disease (AD).

What is the Clarity AD study?

The Clarity AD Study is a pioneering study to test whether BAN2401 can slow memory loss caused by AD. The overall goal of the Clarity AD study is to test whether decreasing the amount of amyloid in the brain using antibody investigational treatment can help slow memory loss associated with amyloid build up.

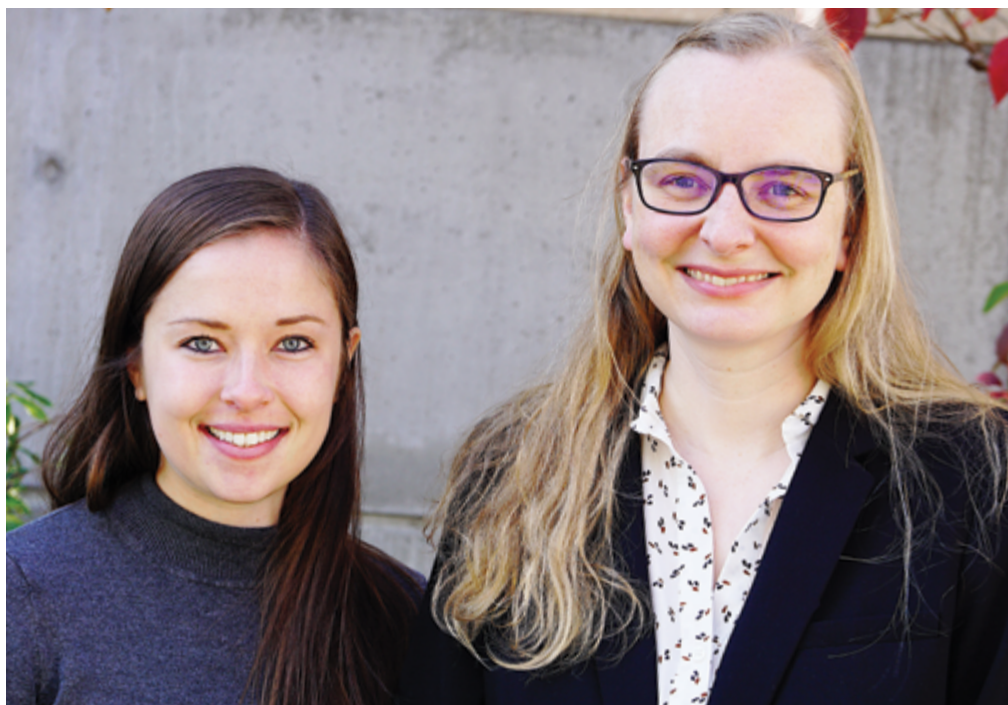
This is a double-blind and placebo-controlled trial. In this type of

research, one group of subjects receives the study drug — the active substance being tested. The other half receives a placebo designed to appear, as much as possible, like the study drug. Individuals in both groups do not know whether they are getting the active treatment or placebo — they are “blind.” The researchers are also kept in the dark about which group is receiving which treatment, making it “double-blind.” The FDA requires double-blind placebo-controlled clinical trials in order to reduce possible bias and errors in clinical trial conduct and to test efficacy of new treatments.

The Clarity AD study lasts for 1.5 years. Participants will be required to visit OHSU every other week. Participants will undergo medical assessments, cognitive testing, mood and behavior testing, and brain imaging throughout the study. At the completion of the study, there will be the opportunity for participants to join an “open-label extension” phase where all participants receive active study drug – BAN2401.

Who can participate in this study?

People ages 50 to 90 who have mild memory problems or mild AD will be selected for screening. We seek to enroll adults who have an “elevated” level of



Kimberly Grzesek, left, Senior Research Assistant, will be the Study Coordinator for the Clarity AD study and Aimee Pierce, M.D., Director of Clinical Care and Therapeutics and Associate Professor of Neurology, will be the Responsible Investigator at OHSU.

amyloid plaque in their brain. Physicians and researchers will use an imaging test called a PET scan, measure the value in cerebrospinal fluid, or both, to determine whether a potential participant has evidence of this amyloid build up. People who do not show evidence of elevated amyloid in their brains will not be able to participate.

Who conducts the Clarity AD Study?

OHSU is one of the lead centers helping to enroll over 1500 people worldwide. The study sponsor is a pharmaceutical company called Eisai Inc. The responsible investigator at OHSU is Dr. Aimee L Pierce, MD, Director of Clinical Care and Therapeutics at the Layton Aging and Alzheimer's Disease Center and an Associate Professor of Neurology within the School of Medicine. ■

If you are interested in learning more about the Clarity AD Study (IRB 20099) or about other aging and dementia research (including if you are a caregiver for someone with dementia and looking for caregiver research participation opportunities), please contact our team at 503-494-7647 or email us at adresearch@ohsu.edu

One study found that people who care for spouses with dementia are at six times greater risk of suffering from dementia themselves compared with people providing care to loved ones with other types of disease, such as cancer.

“We need to figure out how to care for the caregivers,” Lindauer said.

With the new award, ORCASTRIT (Oregon Roybal Center for Care Support Translational Research Advantaged by Integrating Technology) will sponsor surveys, educational efforts and two pilot studies each year.

The first two pilot projects will move forward immediately, including one led by Lindauer using automated sensors in the home. Lindauer will enroll 40 people with dementia and their caregivers to test an intervention aimed at reducing stress in families living with middle to late-stage dementia called STELLA.

To address the care-planning needs of families in the early stages of dementia, **Lyndsey Miller, Ph.D., R.N.**, an assistant professor in the OHSU School of Nursing, will refine and test READYR, an intervention to help families identify and anticipate their needs in the coming years. Miller's study, a family care planning program for early-stage dementia, uses technology to help assess evolving care needs.



Both of the pilot studies will harness in-home monitoring technology to take measure of daily life, such as time spent together, sleep, walking speed, and time spent out of the home. Paired with information reported by participants, Lindauer said these objective measures will paint a much clearer picture of families' lives – and whether interventions such as counseling, exercise activities or socializing makes a difference.

In Oregon alone, the Alzheimer's Association estimates there are 186,000 people caring for partners or loved ones with dementia. ■

OHSU is one of 13 institutions around the country to be designated by the NIA as Edward R. Roybal Centers for Translational Research in the Behavioral and Social Sciences of Aging.

Feeling stressed? Stick to your routine

by Allison Lindauer, Ph.D., N.P.

Assistant Professor and Director, Outreach, Recruitment and Education Layton Aging and Alzheimer's Disease Center



As I write this we are all thinking about COVID-19 and how to protect ourselves and our families. Many of us are staying home and avoiding social events. We don't know what the future holds, and not knowing what to expect can be very stressful. Whether we are worried about our health, our jobs or what the next dementia-related change will be, it can help to keep to our routine.

Try to get up at the same time every day, eat breakfast, exercise, bathe, nap and go to bed at the same time every day. If you need variety in your life, try to get out for a walk, listen to your favorite music, do a puzzle, call a friend on the phone, start a new craft project, or bake a cake. Resist the temptation to stay in bed or loll on the couch (unless that is part of your routine!). Eat healthy foods and limit alcohol intake to one glass (or fewer) per day. Write down your routine to help stick to your plan.

Sticking to a routine gives us a sense of control and predictability, even when things seem out of control. If you need more support, don't forget our reliable partners (see below).

These are my tips. Share yours with me via email (lindauer@ohsu) or a Tweet ([@AllisonLindauer](https://twitter.com/AllisonLindauer)). ■

Support is available. The best way to find someone who can team up with you is to call a local organization. In Portland, the Multnomah County Family Caregiver Support Program offers help and support, 503-988-3646. The Alzheimer's Association can also be a great source of support, 800-272-3900. Oregon Care Partners offers free caregiver training (on-line and in-person), 1-800-930-6851.

Oregon Tax Checkoff for Alzheimer's Research Fund 2019-2020 grant awards

Project Summary:

The Oregon Tax Checkoff for Alzheimer's Research Fund is administered by the OHSU Layton Aging and Alzheimer's Disease Center on behalf of the Oregon Partnership for Alzheimer's Research. These funds are made available thanks to Oregonians donating part of their tax refund to Alzheimer's research.

Priority for funding is given to investigators just entering the field of dementia research. Applicants are investigators in Oregon who are launching their careers, including doctoral students, fellows and junior investigators.

Grants are awarded to clinical, basic or social scientists for support of research that will advance knowledge, treatment or prevention. Potential fields for research include the basic neurosciences, genetics, nursing, social work, epidemiology, sociology, psychology, psychiatry, public health, economics, counseling, delivery of health care services and others relevant to research or practice.

For information about this program, contact Allison Lindauer, lindauer@ohsu.edu, 503-494-6370.

The 2019-2020 research grants awarded to:



Awardee: Nicole Bouranis, MA, Ph.D.-Candidate, OHSU-PSU School of Public Health

Research: Multi-level factors affecting clinical research participation among people with ADRD

Description of project: Over 70,000 Oregonians live with Alzheimer's disease and related dementias (ADRD). A clinical trial's success depends, in part, on identifying people with ADRD who are willing and able to participate in research. This project asks Oregonians living with ADRD to identify the factors affecting their enrollment in clinical research.



Awardee: Selda Yildiz, Ph.D. is a Senior Research Associate at OHSU's Department of

Neurology. Her research focuses on cerebrospinal fluid circulation, sleep and yogic practices using imaging.

Research: Cerebrospinal fluid dynamics in older adults with and without mild cognitive impairment

Description of project: Our team aims to improve our understanding

of a potential connection between cerebrospinal fluid circulation, aging and Alzheimer's disease. We will use magnetic resonance imaging (MRI) to measure cerebrospinal fluid in individuals with and without mild cognitive impairment. We predict this MRI-based approach will help identify individuals most likely to develop cognitive decline.



Awardee: Nora Gray, Ph.D., Assistant Professor, OHSU Department of Neurology

Research: Brain metabolomic changes in the 5xFAD mouse and their modulation by *Centella asiatica*

Description of project: We will evaluate how an extract of a cognitive-enhancing medicinal plant – called *Centella asiatica* – changes the brains of mice affected by Alzheimer's disease. We will compare brain samples from male and female mice affected by Alzheimer's disease with their healthy littermates who have been treated with increasing doses of *Centella asiatica*. Using these scans, we will be able to detect three things: disease-related changes that occur in the brain, the effects of the extract on the brain, and if the changes differ between the sexes. ■



The Alzheimer's Association International Conference® reveals promising Alzheimer's research, offers hope

Sara Kofman, public policy director,
Alzheimer's Association Oregon & Southwest Washington Chapter

Alzheimer's disease is a growing public health crisis. Currently, more than 5 million Americans, including 67,000 Oregonians, are living with the devastating disease. Someone new develops Alzheimer's every 65 seconds. Barring the development of medical breakthroughs, the number of Americans living with Alzheimer's is projected to rise to nearly 14 million by 2050.

In my role as public policy director at the Alzheimer's Association – and having lost my grandfather to Alzheimer's – I know the statistics surrounding this disease are bleak. However, there is hope. Never before have I seen this hope more on display than at the 2019 Alzheimer's Association International Conference® (AAIC 2019). At the end of July, I joined nearly 6,000 researchers from 60 countries across the globe at AAIC 2019 in Los Angeles. The largest gathering of Alzheimer's and dementia researchers, the inspiring conference featured promising clinical trial results, information on potential new diagnostics, research

on care innovations and new insights around Alzheimer's and other dementias.

This year, researchers shared important news on areas such as advances in the search for blood markers for Alzheimer's disease, cognitive decline in the LGBT community, the impact of sleep medications on dementia risk, offsetting elevated Alzheimer's risk through lifestyle interventions and the role of infectious agents in Alzheimer's disease.

Twenty-five Oregon researchers from institutions around the state, including OHSU, attended AAIC 2019. Furthermore, many presented their latest research endeavors at the conference. It was thrilling to see first-hand the interest generated by researchers at OHSU. Dr. Jeffrey Kaye's innovative Life Lab research focuses on aging in place by using technology to monitor participants' level of activity at home. The Sharing History through Active Reminiscence and Photo-Imagery, or SHARP study lead by Raina Croff, Ph.D., continues to yield data on preventing memory loss through

physical exercise combined with active reminiscence.

I know the research taking place at OHSU, across the United States and around the globe will lead to effective treatments, preventions, and one day a cure. It is my sincere hope that someday soon, we will see a world without Alzheimer's. Until that day comes, I will continue to celebrate AAIC as a catalyst for generating new knowledge about dementia and fostering a vital, collegial research community.

About the Alzheimer's Association®

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's.

Visit alz.org or call 1-800-272-3900. ■

Meet the research coordinator, Kate Mincks, Senior Research Assistant

Clinical trials' research needs a study coordinator who is responsible for the research from start to finish. This person works behind the scenes in study start-up and pre-screening, guides participants through informed consent, and assists them during all study visits until study closure. If you have been a part of our clinical trials before – chances are that you have met Kate Mincks. Kate has been with our Center for just 4.5 years and has coordinated more than 10 studies. Read her story below.



I liken my experiences, both as a child and as an adult who works in the field of dementia, to playing the piano, especially the reliable time signatures of Baroque and Classical compositions and how this music differs from the varied, yet still melodic style of jazz.

I began taking classical piano lessons at a young age. I participated in my schools' honor and jazz bands. I tested out of the 8th and 11th grades and graduated as valedictorian of my class. Though I took a one-year hiatus from college, I graduated at 19 with honors and a bachelor's degree in sociology. I always knew my primary interest was in studying aging: how our society views the process of what it means to "age" in our culture. Though I never lost my desire to pursue learning, I took a slight detour in the grand plans of my academically focused youth.

Early in my career, I worked as a certified nursing assistant in memory care. I provided support for impaired individuals who had specialized needs. Many days

this work took an emotional toll, but I found joy interacting with all these individuals and their families, from taking small walks and engaging in conversations to assisting with activities of daily living and functioning

I knew I wanted to remain involved in the field of dementia and was excited when a research assistant (coordinator) position opened at the Layton Center.

As a clinical trials' coordinator, two components of my position take precedence: study participants and protocols (documents that explain why a study is being done and the rules/regulations for conducting the study). Like Baroque and Classical compositions, there are times of predictability: data entry, processing blood and cerebrospinal fluid samples, and regulatory work with Institutional Review Boards (organizations that ensure, as clinical trials' staff, we are protecting the rights and safety of research participants). As in jazz music, there are also improvised moments that

ultimately find their way back to the melody (protocol): treatment-emergent adverse reactions, procedural problem solving, and logistical challenges. Though these are only a few examples of what a study coordinator does, my job would not be possible without the knowledgeable, dedicated, and passionate team at the Layton Center.

Finally, my greatest joy is working with our study participants. I deeply respect the reasons why our participants and their families choose to dedicate their time and energy to be a part of our Center's research. I sincerely believe that they are contributing to finding a cure for Alzheimer's disease. As I am pleased to share a part of myself, I am honored that they, too, would share a part of their lives with me. ■

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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 31 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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