

Alzheimer's Update

The beneficial surprises of caregiver research

Enrolling in a caregiver research study at OHSU inspired Douglas and Jane Grube to reflect upon their life goals and make some important decisions

When Douglas and Jane enrolled in the READyR study, they didn't think it would inspire them to make some life-changing decisions. Being regularly interviewed by study coordinators helped the two reflect upon their own priorities and eventually led them to downsize their home and move to a different part of the city. Volunteering for the study



Douglas and Jane both advocate for increased participation in clinical trials and research studies

not only helped them re-evaluate their lifestyle needs, it gave them a better understanding of each other and of their journey ahead.

"I guess when you give, you receive too. Even though it was not part of the game initially," says Jane. "The universe gives back when you volunteer to give something."

The READyR study is one of the pilot studies originating from ORCASTRAIT, a Roybal Center and a division of the Layton Aging and Alzheimer's Disease Research Center that focuses on caregiver research.

The study connects cohabitating couples with trained research staff who help them assess current and future dementia-related care needs. ORCASTRAIT uses in-home monitoring technology, a combination of digital devices and sensors, along with identification of potential care needs.

"I hope the research leads to some improvement among people living



After moving around the world, the Grubes settled in Oregon to be closer to their two sons and their families

in Portland or wherever," says Douglas. "For us, the study has been very fascinating."

After decades of working in international development, in teaching at universities around

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Global researchers convene in 2021 for the Alzheimer's Association International Conference

by Kaitlyn Bertholet, Regional Coordinator,
Alzheimer's Association Oregon and Southwest Washington Chapter

During the last week in July, over 11,000 attendees from 110 countries joined the Alzheimer's Association International Conference (AAIC), both onsite in Denver, Colorado and virtually. Each year, AAIC convenes the world's leading basic science and clinical researchers, next generation investigators, and the dementia care research community.

The need for conferences like

The dedication of researchers from OHSU and other institutions show us that there is a growing legion of researchers dedicated to the fight against Alzheimer's disease.

AAIC is crucial. Alzheimer's disease and other dementias are a growing global health crisis. Over 6 million Americans, including 69,000 Oregonians and 120,000 Washingtonians, are currently living with the disease. The only way we are going to solve this crisis is through research. Convening leaders in the field creates opportunities to share research discoveries that will lead to new preventions and treatments, as well as improvements in early detection, diagnosis and care.

As a Regional Coordinator and Research Champion with the Alzheimer's Association Oregon and SW Washington chapter, I had the opportunity to attend the conference virtually. Having lost both of my grandmothers to Alzheimer's, I am passionate about advancements in research and deeply hopeful for the day when dementia no longer exists. It was inspiring to learn about studies happening around the

globe, including local research initiatives from OHSU at the conference.

Many pieces of groundbreaking research were featured at AAIC 2021. Themes that emerged from the conference include:

- Advances in imaging and biofluid biomarkers of Alzheimer's.
- Taking action on social determinants research in brain health.
- Risk factors for dementia around the world.
- The impact of the pandemic on research and resilience.

Multiple studies focused on the relationship between air pollution and dementia risk. Building on past research, the

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Learn more at
www.alz.org/AAIC

the world, embarking on several cross-country moves, and being married for over 55 years, the Grubes transitioned into a new chapter of their lives a few years ago. After Douglas's diagnosis with mild cognitive impairment (MCI), Jane became his caregiver. Though there have been difficult moments, they're taking it in stride.

"We're still in the beginning stages. There is frustration, lack of privacy, lack of independence and a lot of grief. And a lot of love," says Jane. "He's been a good husband and father and still is. And I wish he could remember how good he is and how wonderful he is."

For Douglas, living with mild cognitive impairment has simply been "frustrating as hell." It impacts him in small ways, such as having trouble participating in group conversations. However, he

"We like investing in the future of other people," says Jane. "We volunteer so that there are ways for other people to go forward."



Douglas and Jane in their new apartment on the day they first moved in.

doesn't stay silent about his feelings and hopes his story inspires others to be more open, participate in research and take opportunities as they come.

"I would encourage people not to hide so much, and to take opportunities to open up, even to a small amount of people," says Douglas. "Don't hide. There is nothing to be ashamed of. It's an illness. Talk about it."

Though the past several months have been tough, he has gotten support not only from Jane, but also from their two sons and their families, a network of close friends, the study team, and community resources such as the local chapter of the Alzheimer's Association.

"Volunteering for this study is about giving and getting," says Douglas. "Both of us

have experienced this, in our professional lives, where we have provided a service, if you will, and also, particularly in other countries, got service back."

Douglas and Jane did not expect to receive anything from their participation except for caregiver guidance, expert advice about memory issues, and MCI-focused community support.

Unexpectedly, participating in the READyR study helped the Grubes envision their future together, reflect upon their life, and fulfill some long-term goals.

"We like investing in the future of other people," says Jane. "If we have contributed, that's wonderful, because we have benefited too. Volunteering is also a commitment to the future. We volunteer so that there are ways for other people to go forward, not just yourself. You never know what you will get out of participating in a study." ■

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

We have information about:

- The READyR Study
- Aging and dementia research
- Family Caregiver research and support

Every gift counts

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

Associate Professor and Director, Outreach, Recruitment and Education at the Layton Aging and Alzheimer's Disease Center



As the lead of Outreach, Recruitment and Engagement at the Layton Aging and Alzheimer's Disease Center, I often meet people who want to donate to our center. We are dependent on families like the Laytons and people like you to provide the extra support we need. We simply can't do our work without your generosity. Every gift matters. Along with the financial boost, your gifts send a powerful message of support for our team. Working on identifying treatments for Alzheimer's disease, and effective ways to support families, takes determination and a commitment to the "marathon" of this kind of work. We love our work, but like any team, we need fans like you to cheer us on.

That's why we were very excited and

surprised to receive a generous gift of over \$24,000 from the Fraternal Order of the Eagles in June. This vibrant, determined community group pooled their resources from all around Oregon to provide this impactful gift. They presented it to me at their annual convocation. It was exciting for us all. I was speechless with gratitude.

Again, every gift makes a difference. If you'd to talk to me about our Center, I'd love to chat. You're welcome to call me at 503-494-6976. As always, share your ideas with all of us. Follow me on Twitter: @AllisonLindauer.

Thank you to those of you who support this critical work with your gifts, and to the Eagles, for their generosity.

Support is available—call us at 503-494-7467 to learn about our caregiver programs and research. In addition, 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. ■

If you want to support our efforts, please use the enclosed envelope in this newsletter or make your gift online at: Layton.SupportOHSU.org.



The Community Advisory Council provides guidance to Layton Center

Last year a new group of research advocates came together to try and solve an issue: how do we get more participants from diverse communities involved in research studies? Since last September, the Community Advisory Council at the Layton Aging and Alzheimer's Disease Research Center has discussed how to improve outreach strategies in rural, minority and other underrepresented communities, how cultural sensitivities impact recruitment, and how to build stronger connections in those communities.

"We're getting the foundation in place and figuring out what topics to pursue in order to raise awareness of them in the broader communities we're involved with," says Karen Wells, Advisory Council Chair and a Portlander who is also a member of the local NAACP and Multnomah County's Public Health Advisory Board. "We are putting skin in the game by donating our time and energy, and working our networks."

Advisory committee members are paid a modest stipend to honor their work.

The group so far includes

Karen Wells and Ken Hard, an Oregonian living in rural Redmond. Ken is a former caregiver and teacher, as well as a research participant involved in a few telemedicine-focused studies. "This group can really help and inform people," says Ken. "If I could help someone in a way that I was helped, I would like to do that."

Karen and Ken joined the Advisory Council with the goal of encouraging more people from rural, and underrepresented communities to participate in clinical trials and research studies. "With this group, we can help and really inform others," says Ken.

Over virtual meetings, they've brainstormed ideas to increase those numbers, such as networking with community centers, medical providers and care homes to get the word out. Increasing the diversity of participants involved in a research study allows researchers to generalize study results, make more effective therapies and to equalize the benefits of research innovations.

"We are all carbon based units; what affects one unit affects the other," says Karen. "It's the unique differences that often do



Karen Wells, Advisory Council Chair



Ken Hard, Advisory Council member

not get recognized, because no one knew to ask." The Advisory Council hopes to be the one that continues to ask. ■

The Advisory Council meets regularly online. Do you have any suggestions or questions for the Board? If so, please contact: Allison Lindauer at lindauer@ohsu.edu or 503-494-6976.

Research funded by recent grants

Much of the work at the Layton Center is funded by grants and donations. Here we highlight just a couple of the grants funded in 2021.



Principal Investigator: Chao-Yi Wu, PhD., Research data analyst, OHSU Department of Neurology

Research: Supporting Alzheimer caregivers by analyzing the effectiveness of the AARP's Staying Sharp program, otherwise known as the PROACTS pilot study

Funded by: A grant from the National Institute on Aging.

Description of project: We will assess and demonstrate the efficacy of the AARP's Staying Sharp online health program, focusing on the health of non-professional and home-based caregivers, who care for persons with Alzheimer's disease and related dementia. This study has two parts. The first uses a one-time survey to characterize caregivers and understand their

experiences with the Staying Sharp program. The second uses group interventions, where participants follow the Staying Sharp program, and analyzes if the program improves or maintains caregivers' health. In order to assess caregivers' health, the project also uses the ORCATECH technology platform, which features digital devices and sensors that measure health and well-being.



Principal Investigator: Jeffrey Kaye, MD, Director of the Layton Center at OHSU.

Research: Using technology to improve detecting Alzheimer's changes in treatment studies.

Funded by: A grant from the National Institute on Aging.

Description of project: The DETECT-AD study is a new study designed to improve clinical trials for early Alzheimer's disease.

DETECT-AD uses specialized home-based digital devices to see if the

devices will improve clinical trial assessments. This 36-month-long study will simulate a clinical trial to determine how well the home system detects clinically meaningful changes.

Study participants will undergo a brain scan to assess their risk for developing Alzheimer's. After the scan, staff will outfit their homes with devices, including an under-the-mattress sleep sensor, motion activity sensors, an electronic scale and pillbox and a wrist watch activity tracker. Participants will be asked to simply go about their daily routines while these devices collect data in the background.

Scientists will see if there is a change in the digital assessments in four key areas of life activity: mobility (walking speed), cognition (computer use), sleep (time spent sleeping), and socialization (time spent out of home). Participants will be asked to take a daily multivitamin as a study 'drug' to mimic clinical trial conditions.

Using these methods, the study will produce outcome measures that reflect real-world everyday function. Establishing the superiority of these novel methods compared to conventional methods (for example, exams in a clinic) will provide a potential new pathway for speeding the development of much-needed new treatments for Alzheimer's. ■

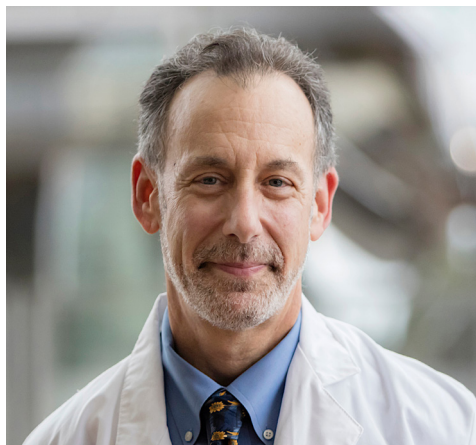
work presented suggests that reducing pollution is associated with lower risk of all-cause dementia and Alzheimer's disease. These researchers looked at air quality over time in association with risk. Additionally, long-term exposure to air pollutants was associated with higher beta amyloid levels in the blood, showing a possible biological connection between air quality and physical brain changes that define Alzheimer's disease.

Some of the first-ever reports of cognitive changes specifically in transgender individuals and gender nonbinary individuals were shared at AAIC. Research has been exploring experiences of dementia within the lesbian, gay and bisexual communities, suggesting these individuals experience a higher rate of subjective cognitive decline (SCD) than heterosexual individuals. SCD is a self-reported experience of confusion or memory loss that is happening more often or getting worse. One study found that transgender adults were nearly twice as likely to report SCD, and more than twice as likely to report SCD-related functional limitations, such as reduced ability to work, be social, or volunteer.

One very exciting announcement was the Bill Thies Award for Distinguished Service to ISTAART, which recognizes a member who

has provided continued and outstanding service to the Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment (ISTAART) community.

This year's inaugural award went to Dr. Jeffrey Kaye, Layton Professor of Neurology and Biomedical Engineering and Director of the Layton Aging and Alzheimer's Disease Center at OHSU. His research spans the fields of genetics, neuroimaging and physiology and focuses on understanding healthy aging. Congratulations to Dr. Kaye



Jeff Kaye, MD, was the recipient of the Bill Thies Award for Distinguished Service to ISTAART, at AAIC's 2021 Conference.

for being honored with this prestigious award!

There was a tremendous feeling of optimism as AAIC 2021 concluded. At any given moment, researchers around the world are seeking new treatments, earlier detection and prevention strategies. As scientists continue to advance new discoveries, we are filled with hope while continuing our work toward a world without Alzheimer's and all other dementia. ■

The Alzheimer's Association is a worldwide voluntary health organization dedicated to Alzheimer's care, support and research. Our mission is to lead the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support. Our vision is a world without Alzheimer's and all other dementia®.

Visit alz.org or call 800.272.3900





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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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Help us *take on the impossible*

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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