Confessions of a research junkie

Below is Ed Parker’s story about being a research participant.

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Have you ever wondered what it would be like to sleep inside a magnetic resonance imaging (MRI) machine with your head wired with electrodes to monitor brain function?

I am participating in four OHSU cognition and aging studies. I guess that as a former Stanford professor who taught human subjects research methodology and as a caregiver for a wife with Alzheimer’s disease, I was predisposed to help find some answers.

I am also a participant at OHSU in the national Alzheimer’s Disease Neuroimaging Initiative (ADNI) study. I like to think that I am included in that study because they needed people who are somewhat normal to compare with people who have the disease. Testing over time should tell whether my assumption of “normal” is correct.

In that study I had two scanning sessions in a positron emission tomography (PET) machine. I was given a colorful radioactive injection prior to each scan that will attach to specific abnormal tissues with a dye that can be detected by the machine. One scan looks for tau tangles and another for amyloid plaques, both of which are found in the brains of Alzheimer’s patients when autopsies are performed after they die.

Dr. Christopher Clark, a former professor of neurology at the University of Pennsylvania and the deceased husband of my domestic partner Anne Clark, was the lead scientist on the research team that developed and got Food and Drug Administration (FDA) approval for the type of injection needed to diagnose Alzheimer’s via a PET scan.

I also had a spinal tap to draw out some spinal fluid to test for indications of Alzheimer’s. Prior to the development of the PET scan technique, a spinal fluid test was the only biological test available that correlated with Alzheimer's patients’ cognitive symptoms.

Both the ADNI study and the MRI sleep study include cognitive testing. Although the researchers do not disclose results unless they detect a fixable medical problem, I can tell from the tests that my memory, which was never good, is getting worse. But I think the disease I have is called “normal aging.”

Anne and I are in one longitudinal “aging in place” study together. Our apartment is monitored with motion sensors and an electronic scale that send data back to OHSU.

CONTINUED ON PAGE 6
Allison Lindauer, Ph.D., N.P., assistant professor and director of outreach, recruitment and education at the OHSU Layton Aging and Alzheimer’s Disease Center, was awarded a Hartford Award for Research and Practice (HARP) for “Dementia 360 ECHO: Using technology to improve dementia care for older adults.” This project is a partnership between the OHSU School of Nursing, Oregon ECHO Network and the Layton Center. The aim of Dementia 360 is to educate clinicians across the state about diagnosing dementia. Dr. Lindauer cares for persons with dementia and their caregivers and conducts research on dementia caregiving and telehealth. She is a preceptor and mentor for students in health-related studies.

Erin Boespflug, Ph.D., assistant professor of neurology at OHSU’s School of Medicine, recently was awarded two early career development grants: a five-year Career Development Award (K01) from the National Institute on Aging and a one-year New Investigator Award from the National Alzheimer’s Coordinating Center (NACC), to expand research developed during her 2017 OADC Pilot Program Grant. These grants will support a series of projects aimed at understanding the intersection of amyloid and vascular pathologies, and how the brain perivascular space serves to maintain brain homeostasis. This research, under the mentorship of internationally recognized experts, including Layton Center Core leaders, Drs. Lisa Silbert (neuroimaging), Randy Woltjer (pathology) and Hiroko Dodge (data), will apply innovative, multifaceted approaches to investigate the clinical and histological features of these spaces and their potential role in brain waste clearance mechanisms. These studies are an initial step toward the long-term goal of identifying novel prevention and treatment approaches to Alzheimer’s disease.

Lisa Silbert, M.D., M.C.R., was appointed as the inaugural Gibbs Family Endowed Professor, announced Dr. Dennis Bourdette, chair and Roy and Eulalia Swank Family Research Professor of neurology at OHSU. Dr. Silbert is currently the director of the Neuroimaging Core and co-director of the Clinical Trials Program at the NIA-Layton Aging and Alzheimer’s Disease Center, and director of the Dementia Clinic at the VA Portland Health Care System. Dr. Silbert is highly deserving of this honor given her productive and novel research on the role of vascular disease in dementia, as well as her dedication to teaching and service within the Neurology Department, School of Medicine and Portland VA Health Care System. Dr. Dan Gibbs and his wife, Lois Seed, recently established this professorship and Dean Sharon Anderson and Provost Elena Andresen approved the appointment of Dr. Silbert. Dr. Gibbs was a neurology resident at OHSU. He practiced in Portland for 20 years and then continued his career by joining our faculty. During those four years, he improved our general neurology practice, co-directed the residency program and introduced our residency program to global health. The generous gift Dan and Lois made reflects their dedication to supporting neuroscience research at OHSU.
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 senior graduate students (for doctoral dissertation research), fellows and junior investigators.

Grants may be awarded to clinical, basic or social scientists for support of research that will advance the understanding, treatment or prevention of Alzheimer’s. 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 Alzheimer’s research or practice.

The 2018 research grants were awarded to:

Catherine Davis, Ph.D., OHSU, research assistant professor, anesthesiology and perioperative medicine: Development and characterization of a novel model of mixed-type dementia

Carolyn Mendez-Luck, Ph.D., Oregon State University, associate professor, human development and family sciences: Racial, Ethnic, and Sexual Gender Minority Caregivers’ Views of Alzheimer’s Disease and Long-Term Services and Supports

Ashley Walker, Ph.D., University of Oregon, assistant professor, human physiology: Interaction of large artery stiffness and amyloid-β on cerebral blood flow

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

Raising awareness about Alzheimer’s in the Asian-American community

Research Associates Dara Wasserman, Nicole Fleming and Sylvia Salazar provided nine lectures on brain health and dementia to over 250 community-dwelling Asian older adults in the Portland metropolitan area earlier this year. Organized in partnership by the Layton Center and the Asian Health & Services Center (AHSC), the lectures were translated into Cantonese, Korean, Mandarin and Vietnamese.

The community learned about the Layton Center’s research and the brain, including different types of memory and the differences between dementia and age-related memory changes.

“Many seniors in our community think dementia is part of the natural aging process. They just accept it and let it be,” said Christine Lau, chief operating officer at the AHSC. “The more information seniors and their families
Get by with a little help from friends

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

Assistant professor and director of outreach, recruitment and education, Layton Aging and Alzheimer’s Disease Center

We sent our daughter off to college in August, and I’ve been reflecting on her schooling to date. When she was in middle school she would go on outings. For each journey, she had a “buddy,” a peer, for whom she was responsible. If a buddy got upset, hurt or lost, her peer would notify the teacher. Their outings were complex. They took the city bus, tramped in woodlands, swam in the ocean. The risk for getting upset, hurt or lost was high. Yet they all made it through middle school and to this day, my daughter, unlike many of us, talks about how she loved middle school.

I think the “buddy system” can work for families living with dementia as well. As family members walk the difficult path of caring for a person with dementia, they too are at risk for getting upset, hurt or lost. Family members who care for those with dementia may find a sense of meaning, opportunity and power in their evolving role, but they may also find the experience burdensome, leading to depression, anxiety and grief. With this in mind, I think it’s important that every care partner have a peer buddy to turn to when they trip up or lose their way (as we all do). In my case it was my sister; for others, it may be a neighbor or friend in a support group. 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.

As our kids learned early in life, don’t go on a journey alone; find a buddy to make the way easier as you go.

Follow me, and other caregivers, on Twitter @AllisonLindauer!
New grant expands Alzheimer’s research

Alzheimer’s causes irreversible brain degeneration, taking with it the thinking skills and memories that people hold dear. At the OHSU Layton Aging and Alzheimer’s Disease Center, scientists work to uncover the causes of and develop treatments for this debilitating disease.

The $200,000 grant from the John L. Luvaas Fund of the Oregon Community Foundation (OCF) will make it possible to scan the brains of clinic patients. A research team led by neurologists Lisa Silbert, M.D., and Jeffrey Kaye, M.D., can then draw correlations between those brain images and real-world data that the center gathers about patients in their homes, including on sleep patterns and movement.

This work will provide the foundation for a new study. “The Luvaas family gift allows us — for the first time anywhere on the planet — to marry these two cutting-edge technologies to find the earliest changes,” Kaye said. “The best treatments are going to be those that start at the earliest times.”

The brain scans feature a molecule labeled with a tiny bit of radioactivity that hooks onto Alzheimer’s pathologies in the brain, Kaye said, making it possible to detect the disease in living people and better understand early indicators. The research will provide data essential for the Layton Center to leverage federal funding, supporting additional research, collaboration and development of treatments.

Today, more than 5.7 million Americans are living with Alzheimer’s. The Layton Center’s internationally renowned research program started in 1990, and is one of only 31 in the U.S. to be designated by the National Institute on Aging.

The Luvaas family’s imprint on Eugene history remains today. Rev. Peter Luvaas moved his family to Oregon from Idaho in 1930, and started the Central Lutheran Church. His son John Luvaas formed the law firm Luvaas Cobb with his colleagues in 1955.

“I still just hear all the time about what an amazing man my dad was and how he helped so many families,” daughter Kris Luvaas Meade said.

“I appreciate the Luvaas family and all the people in Oregon who are contributing to our research. This is not going to be solved by any one person. It really takes a community of scientists, clinicians, patients, family members and philanthropic organizations working together.”

— Jeffrey Kaye, M.D.
via the internet. When we step on
the scale each morning it measures
weight, body fat and pulse rate.
It also gives us the local weather
forecast. That study includes
periodic medical and cognitive
testing and a weekly questionnaire
that we fill out on our computers.

I am also in a study about using
technology for medical monitoring.
For that study, I respond to online
questionnaires about a variety of
topics, including my opinions about
Fitbits, smartwatches and other
wearable devices. I have also tested
the use of electronic pillboxes.

I am not always accepted into
studies I volunteer for. A few years
ago I was rejected in the same
month for two studies, one because
I was too healthy and one because I
was not healthy enough.

The “too healthy” study was
intended to study the effects of
fish oil treatments on cognitive
performance. When I had a blood
draw to test my starting baseline
level, OHSU found that my regular
diet of fish put my measured levels
of omega-3 fatty acids at the high
end of what they hoped to achieve in
the experimental group. Therefore,
I was not eligible to participate in
either the experimental group or the
no-fish-oil control group.

The “not healthy enough” rejection
was because I had had both
prostate cancer and lung cancer
surgeries within the past five
years. Even though both cancers
were completely removed before
spreading to other parts of my body,
I wasn’t considered healthy enough
to participate.

Sometimes studies don’t work out.
For a time I participated in a driving
study that measured my stopping,
starting and braking behavior,
among other things. I think we
eventually figured out they also
were measuring the starts, stops
and braking of the valet staff in the
apartment complex I live in.

I am signed up for one final study. I
have agreed to donate my brain to
OHSU when I die, so researchers can
find whatever surprises it may have
for them that they didn’t anticipate
from the various studies I have
served in.

Oh? You really wanted to know
about sleeping in an MRI machine
after all? There is not much to tell
because I was asleep.

Before the MRI sleep monitoring, I
wore a sleep-monitoring Fitbit and
kept a sleep diary for two weeks
so they had a baseline measure of
how I sleep.

I stayed awake all night before
arriving to my early morning MRI
sleep test. Technicians attached
15 non-magnetic electrodes to my
head to have electrical as well as
magnetic resonance measures of
what was going on in my brain
while sleeping for a couple of hours.

If you would like information about
our current trials and research
participation opportunities at the
Layton Center, please call our
research team at 503-494-7647 or
email adresearch@ohsu.edu.
We are very sad to share with you that Linda, our close colleague, friend to so many, and long-time education core leader for the Layton Center, died unexpectedly this summer.

Linda made tremendous contributions during her 21-year tenure, but also advocated for social justice both locally and globally.

In 2006, recognizing that the Layton Center’s education programs were not reaching persons of color, she connected with members of the African-American community to begin designing culturally specific programs to reach this population. Linda’s commitment to social justice continued in her retirement as she served as chairperson of the board for Green Empowerment (greenempowerment.org).

“How lucky am I to have something that makes saying goodbye so hard.”

– Winnie-the-Pooh (A.A. Milne)

Linda Boise, Ph.D.
May 8, 1948 – July 2, 2018

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3181 S.W. Sam Jackson Park Road
Portland, OR 97239-3098

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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.

Contact the Layton Center at 503-494-6976.

Our team

Jeffrey Kaye, M.D.
Executive director
Layton Aging and Alzheimer’s Disease Center

Ona Golonka, M.A.
Research communications coordinator, ORE Core
Layton Aging and Alzheimer’s Disease Center

Allison Lindauer, Ph.D., N.P.
Director of Outreach, Recruitment and Education (ORE) Core
Layton Aging and Alzheimer’s Disease Center

Jon Mohr
Charitable Giving
OHSU Foundation
503-552-0725
mohrl@ohsu.edu

Natasha Spoden, M.S.
Research assistant, ORE Core
Layton Aging and Alzheimer’s Disease Center

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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