Paul G. Allen Foundation Award will advance new area of Alzheimer’s research

Jeff Iliff, Ph.D., OHSU Assistant Professor of Anesthesiology and Perioperative Medicine and William Rooney, Ph.D., OHSU Associate Professor of Behavioral Neuroscience and Senior Scientist in the Advanced Imaging Research Center, lead one of five teams of researchers from around the world selected to receive Allen Distinguished Investigator grants for research in Alzheimer’s disease. Lisa Silbert, M.D., Layton Center neurologist and researcher will provide dementia expertise for the investigation.

The Paul G. Allen Family Foundation grants seek to open new frontiers in science by supporting early-stage research that incorporates novel, creative and ambitious approaches with the potential to reinvent entire fields. “The Allen Distinguished Investigator projects will provide crucial fresh direction in Alzheimer’s disease research, in part because they include team member perspectives both from within and outside the Alzheimer’s field. We know that these kinds of creative, cutting-edge projects will produce new diagnostics, treatments or even cures for this devastating disease,” reports Tom Skalak, Ph.D., Executive Director for Science and Technology for the Paul G. Allen Family Foundation.

OHSU neuroscientists well represented at AAIC

The 2015 Alzheimer’s Association International Conference (AAIC) attracts dementia researchers from all around the globe. OHSU investigators presented on diverse topics to the international gathering held in Washington DC, July 21-23.

OHSU expertise was showcased by several oral and poster presentations:

Daniel Austin, PhD  Home monitoring to assess mild cognitive impairment in clinical trials.

Adri Seelye, PhD. Computerized cognitive testing and assessment through computer mouse movement.

Lisa Silbert, MD  Comparisons between daily computer use and hippocampal volume.

Deniz Erten-Lyons, MD  A comparison of cognitive trajectories and underlying pathologies.

Katie Schenning, MD  The role of sex in postoperative cognitive decline.

Maysam Asgari  The detection of cognitive impairment in older adults through analysis of the content of verbalizations.

Continued on back page
UPDATE: The C. Rex and Ruth H. Layton Aging & Alzheimer’s Disease Center • September 2015

In 2007, Ken and Marbeth Schiff built a green, efficient home to support good health and indoor air quality as well as their interest in raising their own food. Their small holding in Oregon’s Applegate Valley seemed the perfect location to age in place away from the crowds and air pollution of their former Bay Area home. What they had not planned on was Marbeth’s diagnosis of Alzheimer’s disease in 2009.

Looking back through the lens of his current knowledge, Ken now realizes Marbeth showed signs of developing dementia over several years, though he notes, Alzheimer’s disease was “never in my thoughts.”

Caring for his wife at home in rural Oregon drastically altered Ken’s life. He soon reordered his priorities to focus on her care. He retired from his career as a computer consultant. A self-starter and problem solver, Ken applied himself to the new challenge; he set out to educate himself about the disease, treatment and research. He found help through Oregon’s STAR-C* caregiver training program, which gave him coping tools and the knowledge to recognize what was happening as Marbeth’s health declined. He discovered the resources of the Alzheimer’s Association, especially the 24-hour help line. Eventually, Ken hired in-home providers to assist with Marbeth’s 24-hour care.

Ken discovered the Oregon Brain Bank at OHSU, and since Ken and Marbeth wanted to support Alzheimer’s research, they decided brain donation was a good place to start. Ken contacted Randy Woltjer, MD, PhD of the Oregon Brain Bank to make arrangements for the eventual donation of Marbeth’s brain for research.

After Marbeth’s death in 2012, Ken made a commitment to “work towards the demise of Alzheimer’s disease” using his skills and new knowledge to help others. He has already made arrangements for his brain to also be donated to the Brain Bank.

Though he lives far from the OHSU campus, Ken has developed a growing relationship with the Layton Center as a valuable volunteer and advocate. A designer of software and web sites for 21 years, Ken was drawn to OR-CATECH — The Layton Center’s partner Oregon Center for Aging and Technology. Consulting with the ACT NOW! registry project, Ken assists with web site and communications design for the registry that will soon connect citizens who are interested in participating in and learning about dementia research.

Whenever Ken goes in to town, he wears a shirt sporting an OHSU logo and Layton Center name. With first-hand knowledge of the challenges of living with dementia, Ken wants people to see the shirt and ask him about it. He explains, “If just one person gets help because I wore the shirt and I could pass along information, it’s worth it.”

Oregon trail leads to Oregon Brain Bank
“We had saved up for a rainy day, but we never expected a monsoon” - Ken Schiff, volunteer

Investing in research at The Oregon Brain Bank
The Oregon Brain Bank provides neuropathologic diagnosis and collects postmortem tissue for use in brain research worldwide. In examination of the brain tissue after death, small samples are examined under a microscope to determine the disease process. Brain autopsies provide a valuable resource for research into the cause of illnesses that strike the brain. Research volunteers in some Layton Center Studies donate their brains (both diseased and normal, healthy brains) after death to the Oregon Brain Bank as a contribution to this precious data repository.

*For information about STAR-C in Jackson County, call Carol Terry, 541-471-2863
Dementia care givers at risk for declining health

In 2013, 40 million caregivers in the United States provided an estimated 37 billion hours of care to an adult with limitations in daily activities - AARP Report

The daily challenges of dementia take a toll on family caregivers, resulting in physical, emotional and economic stress. Due to increased stressors, many dementia caregivers often neglect their own health, diet, sleep, and exercise needs. However, research shows that caregivers’ own needs require *more* attention because stress might reduce caregivers’ health and well-being.

In a recent review of 37 research studies* assessing the effects of dementia care giving on caregiver health, OHSU’s Irina Chamine, PhD and Barry Oken, MD examined substantial evidence that the stress of caring for a person with dementia increases the caregiver’s own vulnerability to declining overall health and cognitive function.

The authors also reviewed factors that can help protect caregiver health from harmful effects of stress. Physical activity is essential for decreasing vulnerability to depression and improving sleep quality, as well as for preserving cognitive function. Maintaining social connections, following a healthy diet and using preventive measures, such as necessary vaccinations and health screening tests are also important. Some mind-body approaches, such as mindfulness meditation, that teach self-mastery and a non-judgmental approach to daily challenges are also promising in protecting caregivers from negative stress effects.

This summary points to the need for attention to caregiver health on the part of care providers. Caregivers should be encouraged to protect their own health through preventive measures. Caregivers who take advantage of family and community resource support, and who attend to daily healthful practices and medical concerns will enhance their own well-being and be more effective throughout the care giving journey.

Studies noted in this review measured a variety of health indicators in an objective way, comparing dementia caregivers with non-caregivers of similar age. Among the findings, caregivers were more likely to have:

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<th>Measure</th>
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<tr>
<td>Elevated blood pressure</td>
<td>increased risk for heart disease and stroke</td>
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<tr>
<td>More carotid plaque</td>
<td>decreased blood flow to the brain</td>
</tr>
<tr>
<td>Elevated cortisol levels</td>
<td>associated with sustained stress; increased risk for variety of health problems</td>
</tr>
<tr>
<td>Increased serum interleukin -6</td>
<td>increased inflammation; decreased immune function</td>
</tr>
<tr>
<td>DNA evidence</td>
<td>advanced cellular aging</td>
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<tr>
<td>Decreased quality of sleep</td>
<td>decreased cognitive functioning; vulnerability to depression; increased risk for health problems</td>
</tr>
</tbody>
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Resources for Oregon dementia caregivers can be found at: [www.helpforalz.org](http://www.helpforalz.org)

Dementia care comes home
new program aims to reach more people, promote independence

Evidence suggests that for persons with Mild Cognitive Impairment (MCI) and early Alzheimer’s Disease and Related Dementias (ADRD), making necessary adjustments to routines, keeping social connections, and minimizing mood symptoms help modify the extent or rate of a patient’s cognitive and functional decline. Access to social support services, family caregiver training and regular cognitive assessment is vital for maintaining the ability to carry out the activities of daily living essential for independence.

Challenges to providing care

Of the current 60,000 Oregonians currently diagnosed with ADRD, about 20% (10,000) live alone. Moreover, approximately 100,000 Oregonians live with MCI. In contrast to the increasing incidence of ADRD, the number of licensed professionals trained to provide dementia care remains static. There are not enough care providers to meet the growing demand for dementia services.

Older adults who live in rural areas are even more likely to experience barriers to accessing dementia specialists. Traveling to the city to receive dementia treatment can be challenging. For individuals in poor physical health, with limited income, or who live alone, visits to a clinic may be impossible. Geographic distance, psychosocial challenges, symptomatic limitations, plus static workforce numbers result in limited access to high quality dementia-capable care for the growing numbers who need it.

To address the growing need, the Layton Center at OHSU has developed a direct-to-home video telemedicine care pilot project, Alzheimer’s Care Via Telemedicine for Oregon (ACT-ON), among the first programs of its kind. The ACT-ON project is currently being tested. Our team has been testing the efficacy of cognitive assessment tools for use during a remote, video visit.

Once fully launched, the opportunity for patients to receive dementia care at home through telemedicine could significantly improve access to high-quality dementia care for patients in every corner of Oregon.

Next phase: ACT-ON ADI

If the Center receives additional funding, a more comprehensive telemedicine project is planned. Alzheimer’s Care Via Telemedicine for Oregon – Alzheimer’s Disease Initiative (ACT-ON ADI) will support The Layton Center, along with community partners, to deliver direct-to-home telemedicine dementia care as well support to persons with MCI and ADRD.

The telemedicine program aims to improve state-wide access to dementia care services designed to:

• improve independence and psychosocial outcomes for persons living alone with MCI and ADRD
• delay skilled-care placement for persons with moderate-to-severe ADRD
• reduce burden and grief, and improve social support for caregivers
• improve behavioral symptom management skills for caregivers

It is important to note that telemedicine is not a substitute for primary medical care; each patient in our program must have a local, hands-on primary care clinician with whom our team can work.

To find out more about our current clinical trials, contact Lisa Loree: 503-494-7615 or email adresearch@ohsu.edu.
ACT-ON-ADI will use interactive, real time delivery of telemedicine dementia care using video-conferencing technology. This technology allows face-to-face, highly secure video connections to a patient’s home location. Using a PC or Mac, in desktop, laptop, or tablet formats along with a USB camera, participants will be connected with the ACT-ON-ADI team.

Program management will be led by Dr. Allison Lindauer, Assistant Professor of Neurology at the OHSU Layton Center. Dr. Lindauer is currently managing the Layton Center’s pilot ACT-ON program.

Dr. Adriana Seelye will oversee psychosocial care, support groups, and educational sections of ACT-ON ADI. Dr. Seelye is a clinical neuropsychologist in the OHSU Layton Center. Dr. Seelye will conduct patient visits, group therapy, and neuropsychological assessments. Dr. Katherine Wild, a Layton Center psychologist experienced in dementia behavior assessment and management and will assist with the psychosocial services.

Deniz Erten-Lyons, MD, Assistant Professor of Neurology, OHSU Layton Center, will oversee and participate in clinical care. She will assist with collection and analysis of quantitative and qualitative data for project evaluation.

Once fully implemented, this leading-edge program will bridge the significant gaps in existing dementia care services, and improve access to and delivery of quality dementia-capable care for persons MCI, ADRD and their family caregivers, throughout Oregon and ultimately, across the United States.
Cyclist rides across American for Alzheimer’s research

Twenty three year old Joe Farrell, a graduate of Central Catholic High School in Portland and Seattle University now teaches high school chemistry in Baltimore. This summer Joe rode across the country to raise money for Alzheimer’s disease research. Joe was inspired by his uncle, John Knight, a patient at the Layton Aging & Alzheimer’s Memory Clinic. John has long been an avid cyclist and still bikes 40 miles a day, though he now sticks to the same daily route. Nephew Joe is chronicling his adventure in a blog.

Joe explains his reasons for embarking on his cycling odyssey in support of Alzheimer’s research:

“When I was growing up, my birthdays were always marked by one particularly exciting gift, a daylong celebration day with my Uncle John. He and his wife, Carol, would take time to craft a creative letter that outlined the necessary supplies for our special day. Annually, he would come up with a day full of festivities that could include: a monster truck show, camping at the beach, or even attending a Seattle Mariners game; the day was always tailored to my interests. We would catch up, laugh, and most importantly, bond. I have always cherished these fondest memories from childhood.

“In recent years, Uncle John started to struggle with short term memory. Details began to drift away and he began repeating questions from earlier in conversations. After getting lost while riding a familiar route in Portland, he decided to see a doctor. After a battery of tests, John was diagnosed with early-onset Alzheimer’s disease.

“Fortunately, the disease has been slow to progress and John has been able to maintain a relatively normal life. Attributing this to his active lifestyle, John continues to cycle almost 40 miles every day to maintain maximal blood flow to his brain to help combat his condition. Though he might repeat questions on occasion, he has come to acknowledge his symptoms and continues to attack life with the vivacity that I have always remembered.

“While the medical community has found ways to slow down this illness, there is still no cure for Alzheimer’s disease.

“So, this summer, I am biking across the United States from my home in Baltimore, MD to Portland, OR in order to help raise awareness and money for Alzheimer’s research.

“Cycling serves as a perfect catalyst for this mission as it John’s life source and is a shared passion of his and mine. Frequently our birthday discussions [lead to] stories of his grand biking adventures between Portland and San Francisco and other parts of the United States. I can think of no better way to help raise awareness and funds than through our mutual passion for adventure and touring.”

Joe completed his trek in early August, with Uncle John joining him for the last day, riding together from White Salmon, Washington to Portland.

To read about Joe’s progress across the country, visit: www.gofundme.com/wq9h495d
Portland Art Museum introduces artNOW! cultural outings for dementia families

ArtNOW!, a new offering at the Portland Art Museum, is designed to provide a cultural outing for persons with early-stage dementia and their care partners. ArtNOW! features a thematic and conversational tour of works in the museum plus a related art-making activity. The program is designed as a relaxed and stimulating outing for both care partners and persons with memory loss.

Four consecutive weekly sessions take place on Mondays, when the museum is otherwise closed to the public. The off-hours schedule minimizes confusion, safety concerns or distractions that often present challenges or barriers to the enjoyment of busy public places.

ArtNOW! is modelled after successful programs in other cities. “Meet Me at MOMA” at the Museum of Modern Art in New York City established the evidence-based standard for art museum dementia programs beginning in 2007. The concept has been adapted at numerous cultural institutions in Wisconsin through the Spark Alliance, supported by the Helen Bader Foundation. The Frye museum in Seattle offers a similar program, “here:now.”

Locally, staff from The Layton Center Education Core, The Alzheimer’s Association and Companion Art Studio in Forest Grove have served as initiators, trainers and advisors to the enthusiastic Portland Art Museum staff and docents.

Evaluation of the pilot sessions revealed that participants enjoyed the program and were inspired to go out together more often.

Some key elements of a dementia-friendly cultural experience:

• Activities take place in a quiet, defined space
• Social interaction between partners and with other participants is encouraged; many find that expanding their network of support is an added benefit
• Seating is provided in the galleries and mobility needs are accommodated
• Themes and discussion topics respect the intelligence and experience of participants, without challenging them to recall specific knowledge
• The tour and creative activity are interactive, multi-sensory, and at a relaxed pace

“I think his art, music [and] social acceptance at artNOW! builds his confident sense of self, makes a great outing/event, and I’m convinced it helps to slow the progression of the disease.”
— artNOW! care partner participant

Persons with memory loss and their care partners must register in advance for upcoming artNOW! sessions. Space is limited to 12 participants for each 4-week series.

For more information or to sign up for artNOW!, contact Sarah Holland at the Alzheimer’s Association: sarah.holland@alz.org

Please note “participation in artNOW! in the subject line of emails.

UPDATE: The C. Rex and Ruth H. Layton Aging & Alzheimer’s Disease Center • September 2015
Continued from front page:

Aging is the strongest risk factor for Alzheimer’s disease, yet the age-related changes that render the brain vulnerable to the development of Alzheimer’s disease remain unclear. Members of the OHSU research team are pioneers who recently described the “glymphatic system” in animals, a system that clears away wastes from the spaces between the brain’s cells during sleep. Research carried out in animals suggests that this system may be one of the key ways that the brain gets rid of the protein amyloid beta, which builds up the brains of patients with Alzheimer’s disease.

Drs. Iliff and Rooney’s research team, awarded $1.4 million, will use a combination of established and novel clinical imaging approaches to measure the activity of the glymphatic system for the first time in human subjects.

If successful, this method may be able to provide insight into which patients are vulnerable to the build-up of plaques in the brain associated with Alzheimer’s disease, before clinical symptoms arise. This knowledge could open a window of opportunities for lifestyle interventions and drug treatments to have the greatest chance of preventing or delaying Alzheimer’s disease.

Save the dates for these Alzheimer’s Association Events

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<tr>
<td>Walk to End Alzheimer’s</td>
<td>September 13, 2015</td>
<td>Portland International Raceway</td>
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<tr>
<td>McGinty Conference</td>
<td>November 3, 2015</td>
<td>Oregon Convention Center</td>
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for information visit www.alz.org/oregon

The C. Rex & Ruth H. Layton Aging & Alzheimer’s Disease Center UPDATE

OHSU Brain Institute (OBI) is a national leader in neuroscience patient care, research and education. We provide the most comprehensive care of the brain, spine and central nervous system in the Pacific Northwest. Our nationally recognized neurological programs and centers offer comprehensive care, advanced research and clinical trial opportunities.

The Layton Aging & Alzheimer’s Disease Center is one of 29 NIH Alzheimer’s Disease Centers in the United States 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.

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Charitable giving, Lori Sweeney 503-552-0665

www.ohsu.edu/alzheimers

UPDATE: The C. Rex and Ruth H. Layton Aging & Alzheimer’s Disease Center  •  September 2015