Winter/Spring 2022

DIMENSIONS

The Magazine of the UW Alzheimer's Disease Research Center
UW Memory and Brain Wellness Center

Feature Story: the Memory Hub Opens!

The Memory Hub

A Place for Dementia-Friendly Community, Collaboration, and Impact

In This Issue

Visit the new Memory Hub website:

www.thememoryhub.org

Hello readers! The UW ADRC and the UW Memory and Brain Wellness Center are pleased to bring you Dimensions for Winter/Spring 2022!

This issue marks a new milestone in our Center's history. In the new year, you will be invited to participate in the Grand Opening of the Memory Hub: A Place for Dementia Friendly Communities, a new and nationally unique community center for people with memory loss. The Memory Hub is on Seattle's First Hill, adjacent to and in partnership with the Frye Art Museum. We are proud of our team and many partners and collaborators for bringing this dream to reality, after years of planning and work. The feature article explores the Memory Hub and the people behind this visionary project to create a vibrant place for dementia-friendly community, collaboration, and statewide impact.

This issue also highlights the wisdom shared by the Indigenous Perspectives on Dementia panel at the MBWC's 2021 Dementia-Friendly Communities Conference. You will also learn about findings from recent research studies that relied on the data and specimens donated by research participants enrolled in our ADRC's Clinical Core and in the Adult Changes in Thought Study. Our fall communications intern, Emi Takayama, brings you an article about new ADRC research exploring what microglia—the immune cells of the brain—can tell us about personal Alzheimer's genetic risk. And MBWC geriatrician Dr. Angela Hanson shares her key takeaways from the 2021 Alzheimer's Association International Conference.

As always, we continue to work to advance understanding of Alzheimer's disease and related disorders on a foundation of your trust and support. We appreciate your interest in and support of our work. We hope you take away a sense of our gratitude toward all who contribute to making this work possible. We are thankful to our recent donors. Since 2019, the individuals and foundations who gave to Alzheimer's research in amounts over $2,000 included Richard M. and Maude M. Ferry, the Richard and Maude Ferry Charitable Foundation, Thomas K. and Akari Takayama, Charlotte H. Merritt, Richard J. Hill, Duffy Family Revocable Trust, the Kleeberger Family Foundation, Sarah M. and Richard N. Barton, the Barton Family Foundation, Roy W. and Carolyn W. Chapel, Michael M. and Lisa Crete, the Crete Family Foundation, Darlene and Paul McTaggart, Jayan Eledath, Jacqueline L. and Richard A. Cabe, Jr., Robert P. and Diane Jandl, Barbara A. Traeen, Gerald L. Daily and Janet E. Freeman-Daily, Dean and Sue Eriksen, Dave and Sheree Neal, Catherine Heather and Geoff R. Austin, Carla M. Forester, William H. and Joanne V. Fraser, Paul Carlson and Shawn Hanson, Allan R. Chambard, Eugene C. and Alla V. Chellis, Ron B. Fisher and Sandra J. Lewis, Susan J. Meyer, and collectively, those individuals who donated to Maureen Cardosa's 'Dublin for Dementia' fundraising campaign. These donors and other generous individuals and groups have made it possible for us to move faster in research and reach further into the community than ever before. We recognize the many donors to the Memory Hub on page 13. Your interest makes a difference, and helps us advance the day when threats to memory and brain health will be detected and prevented as the standard of care. Happy reading!

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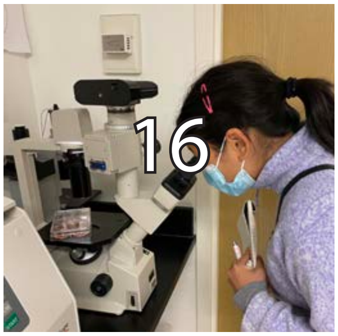

DIMENSIONS The University of Washington Alzheimer's Disease Research Center (UW ADRC) is affiliated with the UW Medicine Memory and Brain Wellness Center (MBWC) and the Veterans Affairs Puget Sound Health Care System (VA). The UW ADRC has been funded by the National Institute on Aging since 1985 to facilitate cutting-edge research on Alzheimer's disease and other neurodegenerative conditions that cause dementia. The UW ADRC focuses on Alzheimer's disease biomarker research and advancing prevention methods and clinical treatment for dementia, particularly through precision medicine. The UW ADRC is also supported by the Friends of Alzheimer's Research, the Ellison Foundation, and members of the public.

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ADRC: uwadrc.org
MBWC: depts.washington.edu/mbwc
The Memory Hub: thememoryhub.org

Facebook: facebook.com/UWMBWC
Twitter: twitter.com/MemoryBrain_UW

DISCOVERIES MADE POSSIBLE BY YOU

These studies used data from research participants in the UW ADRC Clinical Core or the Adult Changes in Thought Study and were made possible in part by funding from the National Institute on Aging.

Tools for Clinical Trials

Parsey C. et al. Utility of the iPad NIH Toolbox Cognition Battery in a clinical trial of older adults. *Journal of the American Geriatrics Society*. 2021**. Carolyn Parsey, Angela Hanson, Emily Trittschuh, Justina Bagger**

As research centers launch more clinical trials for older adults, there is a growing need for effective and efficient tools to assess cognitive changes over time. Computer-based tests have become especially important during the COVID-19 pandemic when long in-person visits are difficult to conduct with older adults.

One commonly used computerized test is the iPad version of the NIH Toolbox for Assessment of Neurological and Behavior Function Cognition Battery (NIHTB-CB test), introduced in 2015. The NIHTB-CB is a 30-minute computerized battery to provide information on a participant's performance in domains of executive function, attention, long-term and short-term memory, visual learning, and processing speed.

This study aimed to demonstrate, for the first time, whether older adult research participants can easily use the iPad test in a clinical trial. The team also compared how well this computer test performed against typical pencil-and-paper neuropsychological tests.

The sample included data from 51 community-dwelling older adults who were part of the Meal and Memory Study, an ongoing meal intervention on cognitive aging. Participants completed two study visits 3 to 5 weeks apart for the clinical trial. At each visit, they took the NIHTB-CB and other neuropsychological measures 3 hours after the meal at each visit.

The study demonstrated that the NIHTB-CB can accurately assess the cognitive function of older clinical trial participants, and that the participants tolerated the test well. The researchers noted practice effects on some of the tests—or the phenomena of a participant showing improvement on a test because of their past experience taking the test. They suggest that practice effects should be considered for researchers who design trials with short time frames. For the wider geriatric research community, the team sees the NIHTB-CB as an effective tool for use in older adult study populations, as the portability allows for greater access to research participation among older adults in assisted living facilities or those who have other mobility challenges. •

Alzheimer's Neuropathology

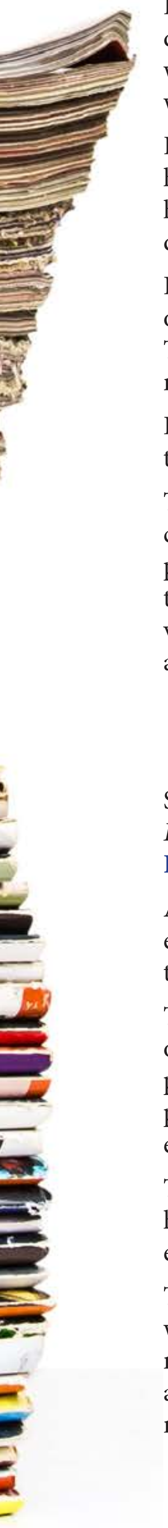
Logsdon AF, et al. Decoding perineuronal net glycan sulfation patterns in the Alzheimer's disease brain. *Alzheimer's & Dementia*. September 2021. **Aric F. Logsdon, Kendra L. Francis, Nicole E. Richardson, Shannon J. Hu, Chelsea L. Faber, Bao Anh Phan, Vy Nguyen, Naly Setthavongsack, William A. Banks, Randy L. Woltjer, C. Dirk Keene, Caitlin S. Latimer, Michael W. Schwartz, Jarrad M. Scarlett, Kimberly M. Alonge**

The brain's extracellular matrix is a three-dimensional network consisting of macromolecules and minerals that provide structural and biochemical support to surrounding brain cells. Specifically, the matrix is made of long chains of sulfate and sugar units, including five main sugar units (A, C, D, E, O). The relative abundance of each unit comprises a matrix 'sulfation code' that controls key neurological functions. Layer upon layer of these sulfate and sugar chains form lattice-like structures within the matrix. These 'perineuronal nets' normally help to maintain the integrity of brain circuits involved in memory and cognition.

This study leveraged ADRC resources to identify neuropathological mechanisms behind changes in the extracellular matrix in Alzheimer's disease. The researchers used postmortem human brain tissue from research participants enrolled in the ADRC clinical core, the Adult Changes in Thought Study, and the Seattle Longitudinal Study, provided by the UW BioRepository and Integrated Neuropathology laboratory.

Using a tool called liquid chromatography tandem mass spectrometry, the team showed that participants with a clinical diagnosis of Alzheimer's disease-related dementia undergo a reorganization of the sulfate sugar chains that correlates with disease progression and cognitive impairment. They found that the brains of patients with Alzheimer's disease exhibit an increase in the abundance of the C, D, and E sugar units, a decrease in the O sugars, and no difference in the A sugars compared to participants without dementia. The next step in this research is to complete true sequencing of the matrix sugar chains, specifically, to determine if Alzheimer's disease changes both the abundance of the sugar unit and the order in which they are added to the sugar chain.

Because these changes in the brain matrix happen very early in the disease process, the researchers suggest that changes in the sulfate sugar code pattern contributes to the start and progression of underlying degenerative processes. This publication implicates the brain matrix sulfation code as a key player in the development of Alzheimer's disease pathology and clinical syndrome, as well as a promising treatment target. •



Brain Resilience

Lee C.S. et al. Application of deep learning to understand resilience to Alzheimer's disease pathology. *Brain Pathology*. May 2021. **Cecilia S. Lee, Caitlin S. Latimer, Jonathan C. Henricksen, Marian Blazes, Eric B. Larson, Paul K. Crane, C. Dirk Keene, Aaron Y. Lee**

In the ADRC Precision Neuropathology Core, research participants are considered "resilient" if their brains show Alzheimer's disease neuropathology changes typically linked to dementia, but they did not develop cognitive decline during life. In other words, resilience refers to the brain's ability to cope and maintain cognitive function, despite having a load of pathology that would be expected to cause symptoms.

Previously, ADRC researchers found that individuals who show TDP-43 protein in their brains upon autopsy, along with the hallmark Alzheimer's proteins of amyloid and tau, were less likely to have been resilient than individuals without TDP-43. They have since developed new methods to better understand differences between resilient participants and participants who had dementia due to Alzheimer's disease, to discover new pathological patterns and gain insights into the disease process.

In this study, ADRC researchers trained two novel, fully automated deep learning computer models to quantify the burden of tau and TDP-43 protein pathology in post-mortem brain samples from fourteen participants in the Adult Changes in Thought Study (ACT). Deep learning is a type of machine learning that can detect meaningful patterns in complex data. In neuropathology, deep learning is starting to be used to classify and quantify different pathologies in brain tissue.

Data came from 7 resilient and 7 age- and sex-matched ACT study participants affected by Alzheimer's disease who donated their brains for research to the UW BioRepository and Integrated Neuropathology (BRaIN) laboratory.

The researchers report that both groups had similar quantities of abnormal tau protein within neurites (a projection from the cell body of a neuron, such as an axon or dendrite). However, the resilient group showed a significantly lower burden of tau protein collected inside neurons, called neurofibrillary tangles, than did the group with dementia. These results suggest that the burden of neurofibrillary tangles is more strongly associated with cognitive impairment than the tau in neurites. This study validates the use of deep learning approaches to quantify clinically relevant microscopic characteristics from neuropathology analyses. •

Air Pollution and Dementia

Shaffer R.M. et al. Fine Particulate Matter and Dementia Incidence in the Adult Changes in Thought Study. *Environmental Health Perspectives*. August 2021. **Rachel M. Shaffer, Magali Blanco, Ge Li, Marco Carone, Adam A. Szpiro, Joel D. Kaufman, Timothy V. Larson, Paul K. Crane, Eric B. Larson, Lianne Sheppard**

A new UW-led study has identified a link between air pollution and elevated dementia risk. The study's findings are based on extensive local data resources—the Adult Changes in Thought Study (ACT), a community-based study on dementia risk factors that launched in 1994 and measurements of air pollution in the Puget Sound area collected since the late 1970s.

The authors report that a small increase in the levels of fine particle pollution (PM2.5 or particulate matter 2.5 micrometers or smaller) averaged over a decade at specific addresses in the Seattle area was associated with a greater risk of dementia for people living at those addresses. In order to estimate air pollution exposure, the researchers used a new air pollution exposure prediction model developed from Puget Sound air monitoring data and low-cost sensor measurements. This model provided estimates of fine particulate matter exposures at the study participant home residences from 1978 to 2018.

The study examined over 4,000 Seattle-area residents enrolled in the ACT Study and identified more than 1,000 people who had been diagnosed with dementia at some point since joining the study. The researchers then compared the average pollution exposure of each participant leading up to the age at which the patient was diagnosed with dementia.

The final analysis showed that 1 microgram per cubic meter difference in the levels of fine particle pollution between residences was associated with 16% higher incidence of dementia. For context, the authors note that in 2019 there was approximately 1 microgram per cubic meter difference in PM2.5 pollution between Pike Street Market in downtown Seattle and the residential areas around Discovery Park, to the northwest. This study adds to the growing body of evidence suggesting air pollution has neurodegenerative effects and that reducing people's exposure to air pollution could help reduce the burden of dementia. •

Find more Discoveries Made Possible By You summaries on the ADRC webpage:

http://depts.washington.edu/mbwc/adrc/page/discoveries-made-possible-by-you

Happy 2022! View our update and New Year's message of thanks to our research participants:

https://www.youtube.com/watch?v=xxkRbW9kiJs

NEW GRANTS AND FUNDING

Researchers in the UW Alzheimer's community recently received the following career awards and grants for exciting new projects. Congratulations to all! Contact gwanucha@uw.edu for additions to this list.

Department of Laboratory Medicine & Pathology

Engineering human brain neurovascular niche for modeling brain diseases. NIA, R21, **Ying Zheng, Jessica Young (PIs)**

Mechanisms of sex differences in risk of developing Alzheimer's disease. NIA, R01, **Jessica Young, Suman Jayadev, Christine Disteche (PIs).** Collaborators: **C. Dirk Keene, Joel Berletch**

The role of TDP-43 in the heterogeneity of Alzheimer's disease. Akari & Thomas Takayama, Research Project, **Caitlin Latimer**

Department of Medicine

The Alzheimer's Disease Sequencing Phenotype Harmonization Consortium. NIA, U24, Leaders: **Timothy Hohman (Vanderbilt University), Mike Cuccaro (University of Miami), Jesse Mez (Boston University), Paul K. Crane**

Understanding and Improving Inequities in Palliative Care for Older Adults with Advanced Dementia and Limited-English Proficiency: A Mixed-Methods Evaluation. NIA, R01, **Rashmi Sharma (PI)** Collaborator: **Kimiko Domoto-Reilly**

Cognition in Primary Care (CPC) Program. CDC/HHS, **Barak Gaster (Director), Annette Fitzpatrick (PI)**. Collaborators: **Jaqueline Raetz, Basia Belza, Monica Zigman Suchsland**

Department of Neurology

Postmortem imaging guided assessment of inflammation in frontotemporal dementia. Akari & Thomas Takayama, Research Project, **Kimiko Domoto-Reilly**

Department of Psychiatric & Behavioral Sciences

Defining the role of age-related glymphatic pathway impairment in amyloid beta plaque deposition. NIA, R01, **Jeffrey Iliff (PI)**

Medical Technology Enterprise Consortium (MTEC) Augmented Neurophysiology of Sleep and Performance Readiness. DOD, **Dawn Kernagis (PI) (UNC-Chapel Hill School of Medicine), Jeff Iliff (Co-PI)**

Positional RNA profiling in patient's brains to discover genes affected by regulatory variants in familial Alzheimer disease. Akari & Thomas Takayama, Research Project, **Olena Korvatska**

Department of Radiology

Cerebrovascular imaging of mild cognitive impairment with suspected non-amyloid pathology. NIA, K01, **Swati Rane (PI)**

Pathological mechanisms of white matter hyperintensities. NIA, R01, **Swati Rane (PI), Jeff Iliff (Co-PI)**

School of Nursing

Development and Useability Evaluation of a Mobile Health Intervention to Support Healthful Dietary Choices in Older Persons with Dementia. NIA, K23, **Oleg Zaslavsky (PI)** Collaborator: **Kimiko Domoto-Reilly**

Division of Gerontology & Geriatric Medicine

Regulation of insulin BBB transport by the astrocyte insulin receptor. NIDDK, P30 Supplement, **Elizabeth Rhea**

MALDI Imaging of glial scar-forming glycans in Alzheimer's disease. NIA, R21, **Kimberly Alonge (PI)** Collaborators: **C. Dirk Keene, Caitlin Latimer, Miklos Guttman**

TDP-43 in Alzheimer's disease. NIA, R01, **Nicole Liachko (PI)** Collaborators: **C. Dirk Keene, Caitlin Latimer, Paul Valdmanis**

Viable Microvessels for the Study of the Microvasculature in Alzheimer's Disease. NIA, R21, **May Reed (PI)** Collaborators: **C. Dirk Keene**

School of Public Health

Virtual Training for Latino Caregivers to Manage Symptoms of Dementia. NIA IMPACT Collaboratory, Pilot Grant, **Maggie Ramirez, PhD, MS, MS**

Washington State University Collaborators

Psychological risk factors, quality of life, community, and brain aging in American Indians. NIA, RF1, **Astrid Suchy-Dicey, Celestina Barbosa-Leiker (PIs)**

Alzheimer's disease biomarkers, vascular risk factors and cognitive variability in aging individuals with diabetes type 1. Alzheimer's Association Research Fellowship to Promote Diversity (AARF-D) Program. **Luciana Mascarenhas Fonseca (PI), Naomi S. Chaytor (Mentor)**

Natives Engaged in Alzheimer's Research (NEAR). NIA, P01, **Dedra Buchwald, James Galvin (University of Miami), John Sai Keong Kauwe (Brigham Young University) (PIs)**

The Adult Changes in Thought Study

The Adult Changes in Thought (ACT) Study Research Program. NIA, U19. PIs: **Eric B. Larson, Paul K. Crane, Andrea Z. LaCroix (University of California San Diego)** Collaborators (UW): **Shubhabrata Mukherjee, Laura Gibbons, Thomas Grabowski, Cecilia Lee, Christine Mac Donald, C. Dirk Keene, Caitlin Latimer, Jessica Young**

- Project 1: Physical activity, sedentary behavior, and sleep in the ACT cohort: The 24-hour activity cycle. **Dori Rosenberg, Sue McCurry**
- Project 2: Cognitively Defined Alzheimer's Subgroups: Natural history, neuropathology, and life course ramifications. **Paul K. Crane, Janelle Taylor (University of Toronto)**
- Project 3: Mechanisms underlying neural protection and toxicity of strong anticholinergic drugs and antihypertensive drugs. **Shelly Gray, Jessica Young** •

alzheimer's association

AAIC 21

Dr. Angela Hanson, MD, researcher and geriatric physician at UW MBWC, reports on what she learned at the Alzheimer's International Conference 2021, including the effects of COVID-19 on the brain, omega-3 fatty acid supplements, the MIND diet to improve brain health and prevent dementia, and promising therapeutics in testing.

This year's Alzheimer's Association International Conference was a hybrid session held both on-line and in-person in Denver, Colorado. I chose to attend on-line, as many attendees did. I was able to attend more sessions because I could watch some of them after hours. However, I was also a bit sad that I couldn't visit my old 'stomping grounds' of Denver where I attended medical school.

A few highlights: The Health Metrics and Evaluation at the University of Washington School of Medicine presented data that global dementia cases are forecasted to triple by 2050, which would mean that 152 million people could be living with this disease. This includes some good news: improvements of global education would reduce dementia risk, but the scientists predict increases in smoking, high body mass index, and high blood sugar levels which would increase rates.

We also learned more connections between poor air quality/pollution and dementia risk, and convincing evidence that improving air quality would reduce the risk of Alzheimer's disease.

Many researchers spoke about the effects of COVID-19 - everything from the effects of the lockdowns on caregiver burnout to the effects of the virus itself on brain structure. Emerging data suggests that COVID has long lasting effects on the brain, in addition to the havoc it wreaks on our lungs and bodies. My colleagues at the VA (Dr. Erickson and others in the Banks Lab) published a review in March about how the SARS-CoV-2 virus can interact with the brain to cause all sorts of problems. These data stress the importance of getting everyone vaccinated to protect against the virus itself, and also from the long term effects on the brain (reference below).

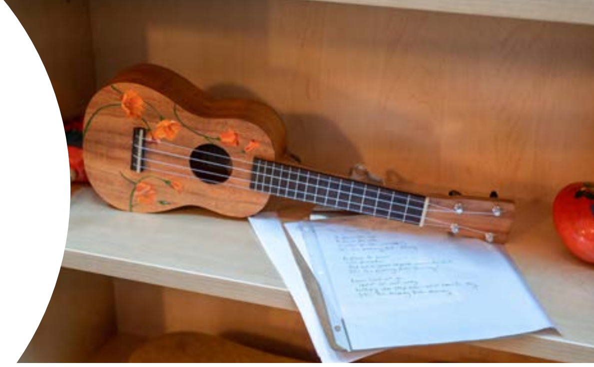
Of course, given that I study connections between diet, metabolism, and dementia, I went to all the talks I could find about those topics. Dr. Yassine at UCLA studies omega-3 fatty acid supplements and lipid metabolism in Alzheimer's disease, and his findings suggest that a part of the brain called the "entorhinal cortex" appears to be responsive to DHA supplementation. This is a part of the temporal lobe important for memory and navigation; Dr. Yassine calls it the "GPS of the brain." This data comes from a clinical trial in adults using algae-derived DHA at 2.125 grams plus a B complex vitamin, and these findings were true for people with and without the Alzheimer's risk gene APOE E4. Of note, the participants in the study had low levels of fish intake. But, he cautioned that these findings were preliminary.

More studies continue to show that following the "MIND" diet - a modified Mediterranean diet that emphasizes healthy foods such as nuts, leafy green vegetables, berries, and fish - helps stave off dementia and cogntive decline. From one of the talks hosted by Rush University, among those without cognitive decline at baseline, following a MIND diet was related to almost 40% lesser odds of having severe widespread tangles and plaques, the pathological changes seen in Alzheimer's disease.

In closing, this wouldn't be a complete story without addressing the medication approved earlier this year by the FDA called aducanumab, or Aduhelm. There were a lot of different opinions expressed about this drug, but I am interested to see how it plays out in 'the real world.' It is my feeling that this medication is complex; the drug has to be given by intravenous (IV) infusion, and not everyone who wants the drug will be able to get it, based on the exclusion criteria.

Fortunately, there are a lot of other medications being tested in phase 2 or 3 trials right now, and some of them are oral pills. For example, there's a drug being tested for a rare form of frontotemporal dementia caused by a genetic mutation. The drug blocks a protein called sortilin and increases granulin levels back to normal both in blood and brain. This trial is very promising for individuals who have a genetic mutation causing this rare form of dementia. For Alzheimer's disease, there are several promising medications that affect both tau and and amyloid proteins, and they are being tested in people right now. Similar treatments to aducanumab are being studied to help us understand how long someone might need to be on these medications. •

Reference: Erickson M et al. Interactions of SARS-CoV-2 with the Blood-Brain Barrier. *Int J Mol Sci*. 2021. https://pubmed-ncbi-nlm-nih-gov.offcampus.lib.washington.edu/33800954/



The Memory Hub

A Place for Dementia-Friendly Community, Collaboration, and Impact

The Memory Hub started as a big dream. It was a dream to create a home for the support, education, and engagement programs that the UW Memory and Brain Wellness Center offers for people with memory loss and their families—a warm, welcoming, and non-clinical place, where someone with memory loss is a person, not a patient or research participant. Over time, the dream expanded to involve a vibrant group of partner organizations, and a vision to spread dementia-friendly programs from Seattle across the state!

The Memory Hub: A Place for Dementia Friendly Community, Collaboration, and Impact is finally opening its doors at a Grand Opening on March 23, 2022! This unique community center aims to make the memory loss journey less daunting and to improve quality of life for people with memory loss and their families by providing resources and creative activities, in a community of support.

> **“To me, the Memory Hub represents the concern and care that we have for the aging population and their families and caregivers. It’s a loving, caring, compassionate concern. It addresses the physical and psychological needs of the growing dementia community. I like to think of it as ‘gifts for life’. ”** – Richard M. Ferry

The UW Memory & Brain Wellness Center has long been committed to building dementia-friendly communities, alongside our partners. What is a dementia-friendly community? It is a neighborhood, town, or city which people with memory loss and their loved ones are respected and included and can participate confidently in community life. Local efforts to build dementia-friendly communities abound, from dementia-friendly walking groups with Seattle Parks and Recreation, to the Frye Art Museum’s Creative Aging programs for people living with dementia and their families. Now, people living with memory loss and alongside others involved in the dementia-friendly community movement have a physical place – the first of its kind – to gather, create, network, and bring visibility to these efforts.

“Community can be the difference between feelings of despair and feelings of hope — the feeling that you can get through this,” says Marigrace Becker, program manager for community education and impact, and the director of the Memory Hub. “By creating the Memory Hub, we are ensuring that people with dementia are woven into the fabric of community life, rather than sidelined and forgotten.”

The benefits of dementia-friendly community are known best by its local members. “Having a community that is not afraid of Alzheimer’s disease is priceless,” says caregiver Carla Griswold, who is a MBWC community advisory group member alongside her spouse Kirk. “They acknowledge that this new life will be entirely different from the life we previously had with our loved one. Within this community, we have learned how to live with Alzheimer’s, and we have made lifelong friends. We sustain each other. I cannot imagine traveling this road without them.”

The dream for the Memory Hub turned into a reality, after a matching gift from the Richard and Maude Ferry Charitable Foundation. We are also grateful for the many generous gifts from individuals, foundations, and organizations. A complete list of all Memory Hub donors appears at the end of this article.

“I am excited about the Memory Hub,” says Richard M. Ferry, founding donor for the project. “I think Marigrace Becker is going to bring together a cohort of talented people from different organizations to make this a national model for innovation in dementia programs and support for many folks in this community, as well as in the country and maybe globally.”

Conveniently located in Seattle’s First Hill neighborhood, the Memory Hub is housed in a building owned by our founding community partner the Frye Art Museum. “It’s not just that the Frye Art Museum is geographically close, it’s that they’re philosophically close to us,” said Thomas Grabowski, MD, director of the UW Memory and Brain Wellness Center.

For ten years, the Frye Art Museum has offered Creative Aging programs for adults to engage in creative lifelong learning, including accessible museum tours and art classes for people living with memory loss and their care partners. “This is a unique partnership between a memory disorder clinic, our partners and a free art museum. Can you imagine a less stigmatizing environment to build dementia-friendly community?” asks Grabowski.

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"Being part of the Memory Hub community brings new opportunities for collaboration with like-minded organizations and individuals dedicated to bringing joy, respect, and dignity to people living with dementia while destigmatizing the disease," says Mary Jane Knecht, Manager of Frye Art Museum Creative Aging Programs. As a Memory Hub on-site collaborator, the Frye will co-sponsor the monthly Alzheimer's Café event and support other art-related activities.

When visitors enter the Memory Hub, they will find a gathering space, lecture hall, gallery of art made by persons with memory loss, a memory loss resource center/library, an arts-based adult day program, a social worker to assist with navigating community resources, a memory garden, and so much more. Our on-site partner organizations helped to create this wide array of features and resources. Read on to learn more about what makes the Memory Hub a vibrant place of community, collaboration, and statewide impact.

EXPLORE THE MEMORY HUB!

A New Home for Wellness and Support Programs and Community Resources

The Memory Hub brings staff from our on-site collaborator organizations together to co-locate under one roof, to offer wellness and support programs for the community. For example, Elderwise, a local adult day program, is offering its structured program of arts, exercise, discussion, and shared community for people with dementia, which provides respite for caregivers. Full Life Care is running Dementia Training for Family Caregivers, an evidence-based virtual and in-person course with individualized coaching that helps family members better support their loved ones.

The Memory Hub finally provides a home base for UW MBWC strengths-based and dementia-friendly programs, especially ones that require a large activity space. "It's been incredibly important for me to make our programs and services as accessible as possible, which includes taking them out of a medical or hospital setting when appropriate," says Kris Rhoads, PhD, associate professor of UW Neurology and founding member of the Memory Hub. "While we've benefitted from the kindness and generosity of others offering their space for our group lifestyle and behavioral intervention, ADAPT (Applied Daily Activities to Promote Thinking), having a permanent home program for this will enable us to optimize the format and schedule in ways that would otherwise be impossible."

The Tech Lab at the Memory Hub is a brand-new addition thanks to MBWC neuropsychologist Carolyn Parsey, assistant professor of UW Neurology. This program will offer regular hands-on consumer technology demonstrations for people with memory loss and care partners, and trainings to learn how technology can promote social connection, emotional and physical wellness, and independent living.

Regularly offered Memory and Brain Wellness Center community programs and events will remain a hybrid between in-person at the Memory Hub and virtual format on Zoom for the time being. You can explore all the offerings and updates on our new website: www.thememoryhub.org.

Thanks to the Alzheimer's Association, a memory navigator will be available during open hours to provide resources to people with memory loss and caregivers. "So many individuals and families that receive a memory loss diagnosis or are experiencing memory loss don't know where to go," says Em Brulotte, Helpline Coordinator and Care Consultant at the Alzheimer's Association, who will fill this on-site role. "The Memory Hub creates a space where the guidance of next steps and support can be established—a place where the concerns, needs, and the journey that is memory loss are at the forefront."

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MEET THE COLLABORATORS

- UW Memory and Brain Wellness Center www.depts.washington.edu/mbwc
- Frye Art Museum www.fryemuseum.org
- Alzheimer's Association, Washington State Chapter www.alz.org/alzwa
- Elderwise www.elderwise.org
- Full Life Care www.fulllifecare.org

WHAT DOES THE MEMORY HUB OFFER?

- Support Groups
- Caregiver Education
- Creative Engagement
- Library & Resource Center
- Art Gallery
- Memory Garden
- Elderwise Adult Day Program
- 'Memory Navigator' Care Consultant
- Public Lectures
- Networking & Professional Development Events
- Annual 'Reframing Dementia' Conference
- And more!

Weekly public tours

11-11:45 a.m. Thursdays, January 20 – March 17

Grand Opening Celebration

2-4 p.m. Wednesday March 23

- Live music
- Refreshments
- Program demonstrations
- Ribbon cutting and more!

Activities will follow current COVID-19 guidelines; virtual options also available. Space is limited, please sign up online at:

www.thememoryhub.org

Questions:

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Frame of Mind: A Gallery of Art Work Created by People Living with Dementia

The Memory Hub features the ‘Frame of Mind’ exhibit, a rotating quarterly art gallery of works created by people living with dementia. The art currently on display was created by the participants enrolled in the Elderwise adult day program in the early spring of 2020.

The Elderwise artists used a wet-on-wet watercolor technique for these works, painting with watercolor paint on wet paper. This method encourages the paint to flow across the paper in exciting, unpredictable patterns and works well for a variety of ability and experience levels. For this exhibit, Elderwise staff selected at least one painting from each participant, based on its representation of the artist’s own personal style and way of using color.

Lindsay Waltner, program coordinator and a program facilitator for Elderwise, witnessed the creation of the art and recently helped install the inaugural show. “The participants had such wonderful camaraderie, and each individual came to the table with an open heart and so much kindness,” says Waltner. “Because I had the privilege of spending time with the artists as a program facilitator, I loved being able to revisit the paintings while working on this show because each painting reminds me of the person who created it. My hope is that the gallery brings people joy and that the array of artistic styles among the paintings will celebrate the unique beauty that people with memory loss can share with us. The Elderwise artists show us that we can continue to express who we are regardless of physical or cognitive changes.”

> **“As our programming matures and we find new synergism within this space, it’s going to be a very compelling experience. The Memory Hub is unlike anything out there. It’s going to inspire people.”**
> - Dr. Thomas Grabowski

The gallery is now viewable on our website’s virtual gallery www.thememoryhub.org/exhibit and at the Memory Hub during business hours starting this spring.

Statewide Impact Initiatives

While a variety of memory loss programs and initiatives thrive in urban areas like Seattle, people with memory loss and their families, and practitioners, in other parts of the state regularly ask, “what about us?” There has yet to be a place focused primarily on training related to dementia-friendly communities, spreading best programs and practices from Seattle around the state.

The Memory Hub is positioned to drive statewide impact, working in alignment with other broad efforts such as the Dementia Action Collaborative, a partnership implementing the Washington State Plan to Address Alzheimer’s and Other Dementias. We also closely partner with Momentia, a grassroots movement empowering people with memory loss and families to stay active and connected in the community. To inspire and equip other communities to offer strengths-based programs and dementia-friendly initiatives, we’ll offer trainings on program implementation, opportunities to observe programs, consulting and advice, and an annual symposium.

Hosted in the Memory Hub’s on-site Zoom room, the Dementia-Friendly Washington Learning Collaborative meets online every month to support expansion of dementia-friendly community efforts, learning from and sharing with each other around a common theme. The Memory Hub will also provide a home base for Dementia Friends, a public awareness project working to build understanding and remove the stigma that people and their care partners face. Dementia Friends trains volunteers to give an hour-long community information session about what it’s like to have dementia, and how to be supportive to neighbors, friends and family members who live with dementia.

At the heart of our effort to help improve dementia care is Project ECHO Dementia, a web-based videoconferencing learning model for frontline care providers from Washington State. “The Memory Hub’s partnership with the Dementia Action Collaborative is fundamental to our mission of driving statewide impact,” says Kris Rhoads. “I’m especially excited to have a state-of-the-art home for Project ECHO Dementia, our virtual telementoring clinic designed to help primary and specialty care providers from around the state to diagnose and care for individuals and families living with memory loss and dementia.”
Learn more: www.thememoryhub.org/page/professionals

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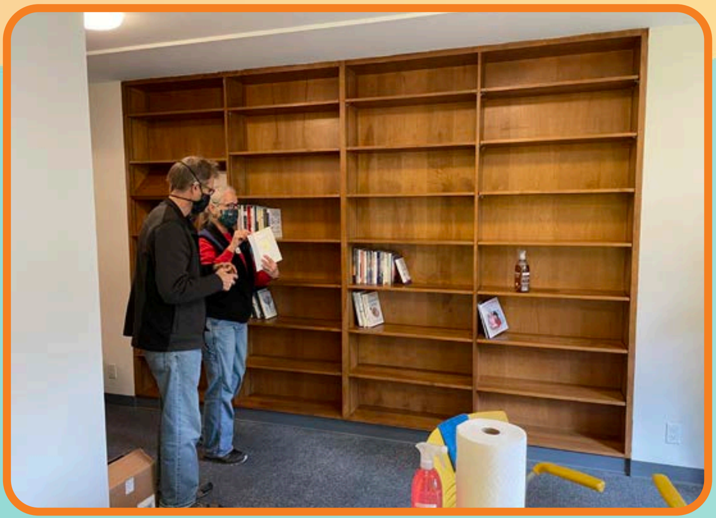
The Memory Hub's on-site Zoom room

The Memory Hub's conference room for gatherings, lectures, trainings, networking events, and more!

Outside the Memory Hub in January of 2022. Our partners at WSU Institute of Research and Education to Advance Community Health (IREACH) visited to take a tour!

Collaborators gathered in the common area to celebrate progress towards opening the Memory Hub!



Volunteers Karen and Scott help arrange the Memory Hub library in November of 2021.

At work in a past Dementia Friends training. The Memory Hub will provide a home base for Dementia Friends.

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Maude's Garden: A Nature Sanctuary for Joy, Healing, and Learning

Inspired by the interest in nature experiences in our community, the Memory and Brain Wellness Center is creating Washington State's first public memory garden for people living with dementia. Maude's Garden is named in honor of the late community advocate and philanthropist Maude M. Ferry, beloved spouse of our founding donor Richard M. Ferry. This botanical garden is uniquely designed to enhance the lives of people living with dementia, as well as provide a relaxing, restorative space for all.

The garden will serve as a spot for drop-in gardening, socializing, and nature-based activities, such as horticultural therapy and an adaptation of the Garden Discovery Walks program. We are thrilled to be working with Stone Soup Gardens, a sustainable local landscape company, to build the garden infrastructure. They are leaving all of the planting to us!

Maude's Garden has an interesting origin story in the Garden Discovery Walks, a program the UW Memory and Brain Wellness Center offers in partnership with Seattle Parks and Recreation. From 2017 to 2020, the program involved a monthly in-person tour of a local public garden followed by a creative, nature-inspired activity.

"The gardens we visited were incredibly welcoming and always full of beautiful surprises," says Genevieve Wanucha, science writer at the UW Memory and Brain Wellness Center and green space project lead for the Memory Hub. "But we began to imagine having one special garden that would pose no unexpected barriers to accessibility and provide a familiar, dependable environment and feeling of belonging for people living with memory loss. We dreamed of a botanical sanctuary that our community could have a hand in designing and tending."

The green space behind the Memory Hub became the perfect location for the envisioned memory garden. The garden design process, over the last two years, has incorporated feedback from community members living with memory loss and care partners, as well as lessons learned from the Garden Discovery Walks program and a visit to our friends at the Portland Memory Garden. We are excited for a new community partnership with the team at the Bloedel Reserve on Bainbridge Island, who will contribute advice and feedback on our planting plan.

We are incredibly grateful to our community donors who made major financial investments in this garden. Their generosity ensures that Maude's Garden will reach its fullest potential as a source of joy, healing, and learning for the local memory loss community. Learn more about Maude's Garden at www.thememoryhub.org/garden. >>>

Memory garden focus group, February of 2020

**Memory Garden design plan, 24" x 18"
Peach Jack, 2020
Charcoal, parchment paper**

The space before garden building started in January of 2022!

Welcome to the Memory Hub!

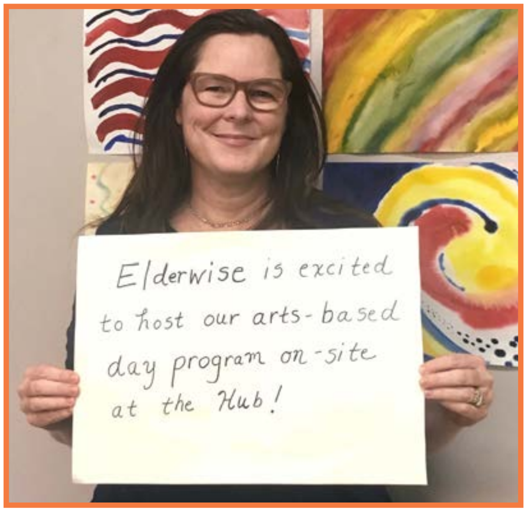
We are excited to finally welcome people into this new space. We are offering small group tours of the Memory Hub this winter, leading up to a Grand Opening event on March 23, 2022. All events and programs will follow current COVID-19 guidelines. Check out our new website at www.thememoryhub.org to find our calendar, updates, news, and links to register for programs and events.

The Memory Hub models what a community of support looks like for people with dementia and memory loss, but it also depends on the community for support going forward. Its success depends on other visionary donors who understand the importance of supporting people with memory loss and their families at every step of the memory loss journey.

The Memory Hub team is grateful for the moral and practical support of the MBWC team, the MBWC community advisory group, on-site collaborators especially founding partner the Frye Art Museum, support of UW Medicine leadership, UW Advancement, UW Real Estate, UW IT, web designer Jonathan Henricksen, our funders, and our memory loss community members who tirelessly cheer on the Memory Hub.

“I am so looking forward to walking through the bright halls of the Memory Hub to meet even more people on this journey,” says caregiver Carla Griswold. “It will offer a sigh of relief, a balm to chaos we live with every day. I can’t wait.”

Visit the new Memory Hub website at www.thememoryhub.org. For questions, please contact the director of the Memory Hub, Marigrace Becker: 206-744-2190, mbecker1@uw.edu. •



Thank you to the people and organizations who donated funds to support the Memory Hub!

Richard M. and Maude M. Ferry
The Richard and Maude Ferry Foundation
Charlotte H. Merritt
The Anderson Foundation
Emerald Heights Retirement Community
Paul R. and Phyllis A. Seegers
Aaron J. and Gwen Colwell
Peter W. and Merle Mullin
Peter W. Mullin Family Charitable Foundation
Debby and Kristian B. Hanssen
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Denise Truxal
Alan D. Findlay
Mary and Michael W. Hunstad
Karen I. Millward
Kevin Brown
Phyllis R. Stern
Gail Eileen Efroymson

The Memory Hub

Meet the Memory Hub On-Site Collaborators!

Learn about the people you'll meet at the Memory Hub.

Marigrace Becker is the UW Memory and Brain Wellness Center's Program Manager for Community Education and Impact and director of the new Memory Hub. She is passionate about building dementia-friendly communities and excited to see the way the Memory Hub will create new opportunities for collaboration and innovation. In her spare time, she enjoys running, bringing people together, and celebrating whenever possible.

Kris Rhoads is a neuropsychologist at the UW Memory and Brain Wellness Center and founding member of the Memory Hub. He is most excited about partnering with people and families around making positive changes to live well with memory loss and is grateful to be able to take this work to the collaborative space that is the Memory Hub. In his spare time, his world mainly revolves around his wife and daughter, their Chocolate Lab (Mango), and his community of fellow (mostly middle-aged) rock climbers.

Mary Jane Knecht is Manager of Creative Aging Programs at the Frye Art Museum. She is excited to collaborate with the Memory Hub community to offer experiences that celebrate present-moment awareness, new possibilities for creative expression, and opportunities that deepen our shared humanity. Dividing her time between Seattle and the Olympic Peninsula, she enjoys swimming, gardening, and life with her husband and two cats.

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Allyson Schrier is the Program Manager for Project ECHO Dementia, and helps support the Dementia-Friendly Washington Learning Collaborative. She is grateful to work on projects that help people living with dementia and their families thrive beyond their diagnosis. She lives in the 'Issaquah Alps' where she loves communing with nature on foot or on her mountain bike.

FRYE
ART MUSEUM

Carolyn Parsey is a neuropsychologist at the UW Memory and Brain Wellness Center and enjoys helping people use technology to make day-to-day life with memory loss a little easier. At the Memory Hub, she'll lead workshops and demonstrations of helpful technologies. She is excited to collaborate with others on projects that promote independence and wellbeing for people with memory loss. When not at work, you'll find her planning her next travel adventure, officiating soccer matches, rockhounding for gemstones, or playing fastpitch softball with fellow college 'has-beens'.

Genevieve Wanucha is the science writer and website manager for the UW Memory and Brain Wellness Center. At the Memory Hub, she helps to create Maude's Garden and coordinate the memory garden volunteers, communications, and planting. She works alongside garden team members Peach Jack, Laura Rumpf, and Marigrace Becker. Genevieve is also a botanical artist who works in watercolor and colored pencil and will soon be a new mother.

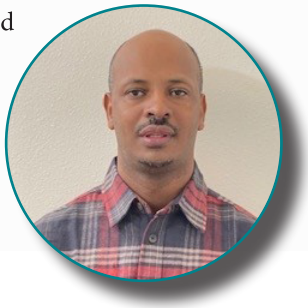
Em Brulotte is the Helpline Coordinator/Care Consultant for the Alzheimer's Association, and a Care Navigator for the UW Medicine Memory and Brain Wellness Center. They work with families and individuals who are experiencing memory loss by providing consultations and resources. Em is excited to be a collaborator within the Memory Hub as we work to create a community of dementia related programs and services. While out of the office, Em enjoys time outdoors, cooking, and spending time with friends.

Annie Koziol has worked with Elderwise for many years and is now the Director. She looks forward to the incredible opportunity of collaborating with the dementia-friendly organizations coming together at the Memory Hub. In her spare time, she gardens and has fun with her children, grandchild, and friends.

Sandy Sabersky is co-founder and board chair of Elderwise and is co-author of *The Elderwise Way: A Different Approach to Life with Dementia*. She is looking forward to in-person meetings again and being in community with participants in the Elderwise day program. Sandy is happy to be a part of the Memory Hub team. Sandy enjoys being out in nature.

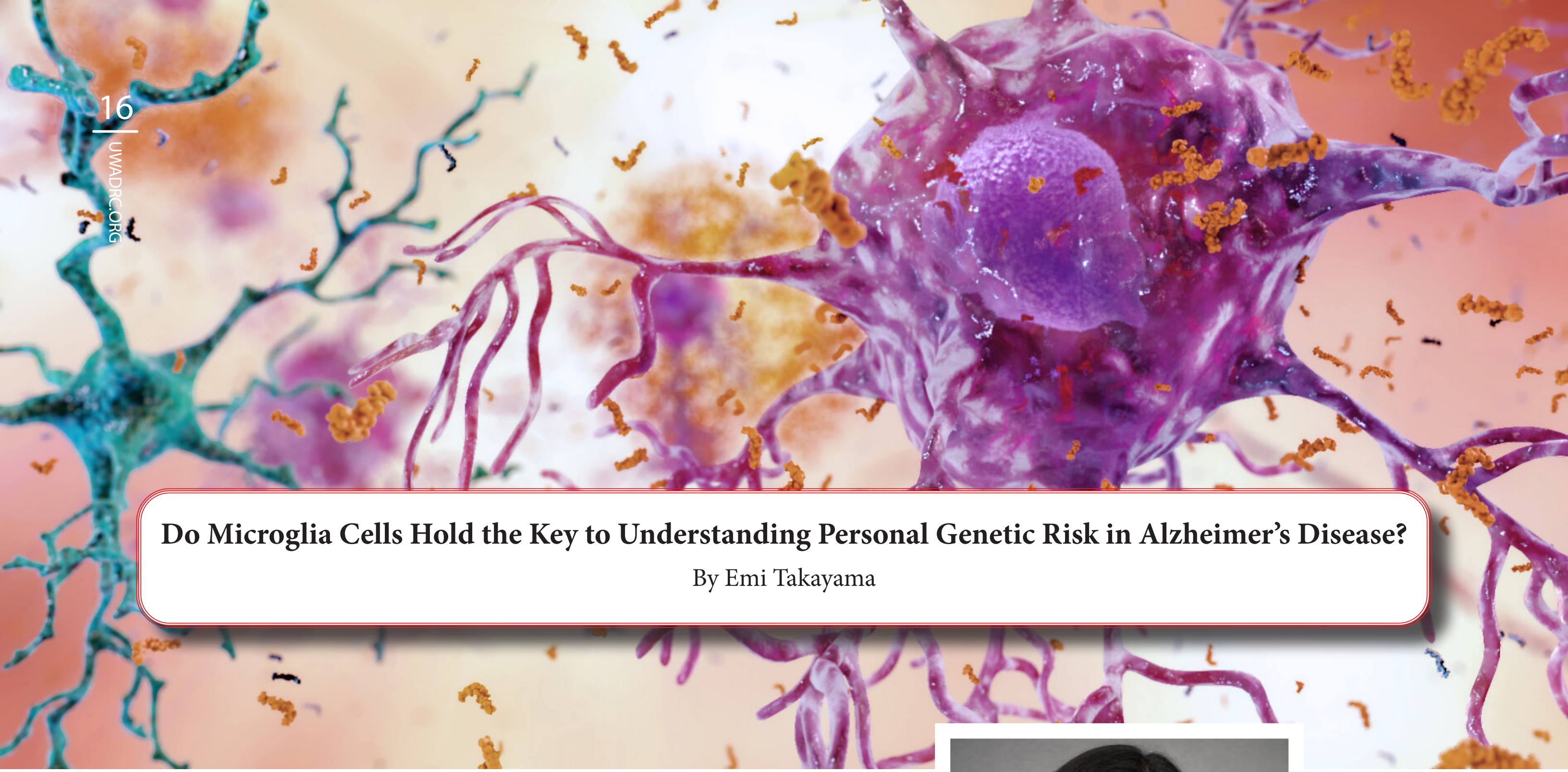
Lindsay Waltner is the Program Coordinator and a Program Facilitator for Elderwise. Lindsay enjoys finding connections and sharing her passion for art with the Elderwise participants, and is excited to be part of a collaborative dementia friendly community at the Memory Hub. When she isn't working at the Memory Hub, Lindsay loves cooking, traveling, and being an aunt.

Tegenu Negi is the Training and Outreach Specialist at Full Life Care. He is excited to provide the evidence-based STAR-Full Life Care dementia training for family and in-home caregivers. He sees being involved at the Memory Hub as a great opportunity to collaborate with other programs and expand services to communities. In his spare time, he enjoys traveling, gardening, and playing ground tennis.



Rena Ferretti is the Director of Community Programs at Full Life Care and enjoys bringing people together to make the world a better place. She has worked in the dementia community as a support group facilitator for over a decade and holds dear the relationships that have developed over that time. In her spare time, she enjoys gardening and fly fishing.

www.thememoryhub.org



Do Microglia Cells Hold the Key to Understanding Personal Genetic Risk in Alzheimer's Disease?

By Emi Takayama

Imagine a garbage truck, bustling down your street, emptying trash into the rear, crushing it inside, and then bringing it to the dump or recycling center. What happens when the truck malfunctions? It may fail to compress the emptied waste and overflow with litter or, even worse, it may capture and damage something valuable like a mailbox or car. Believe it or not, this concept could relate to the development of Alzheimer's disease in adults.

All of our brain cells run a protein transport and waste disposal network called the endolysosomal system. This system is involved in internalizing, packaging, and trafficking proteins and trash to different parts of the cell. Brain cells depend on a healthy endolysosomal system to handle a variety of jobs. For example, microglia, the resident immune cells of the brain, use this system to eat and digest invaders and dead neurons. They helpfully gobble up and dispose of cellular waste, such as amyloid protein, that could otherwise build up and set the stage for Alzheimer's disease.

"This system that helps cells process and degrade waste is known to be dysfunctional in neurons in Alzheimer's disease patients really early on, even potentially prior to the onset of cognitive symptoms," says Katherine Prater, PhD, a post-doctoral research fellow at the UW School of Medicine who studies microglia in the Jayadev Lab. "And so it's possible that endolysosomal system dysfunction is also a driver of Alzheimer's pathology progression."

The ADRC's Jessica Young, PhD, assistant professor of pathology at UW School of Medicine, hypothesizes that problems with this cargo transport system can cause brain cells to malfunction. "If the endolysosomal pathway goes awry, microglia may not internalize amyloid protein at the correct rate, preventing the cell from degrading it properly, or it may cause the cell to become overactive and secrete too many inflammatory molecules," she says. Just as a garbage truck can spill trash because of an internal malfunction, microglia may leak waste and activate a harmful immune response if the endolysosomal pathway is impaired.

Suman Jayadev, MD

Jessica Young, PhD

In a new project funded by the National Institute on Aging, an ADRC team led by Young and Suman Jayadev, MD, associate professor of neurology at UW School of Medicine, are working to document exactly how the endolysosomal pathway is disrupted in both microglia and neurons from Alzheimer's disease patients. But Alzheimer's disease doesn't affect every patient in the same way, so the researchers want to understand how an individual's genetic background influences their own disease process, and ultimately, how they may respond to targeted treatments.

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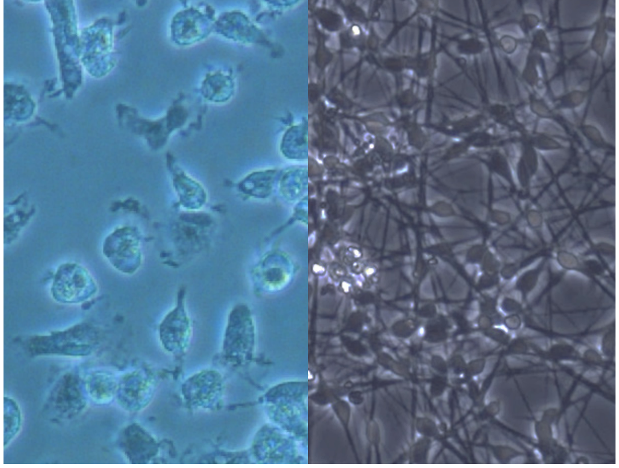
Image: Brain Inflammation from Alzheimer's Disease. Credit: National Institute on Aging



Left: Lab cultured human microglia cells at 20 X magnification. Right: Lab cultured human neurons at 10 X magnification. Courtesy: Young Lab

The author, Emi Takayama, views human microglia cells through a microscope in the Jayadev Lab.

Over the last decade, large studies called genome-wide association studies have identified many genetic variants linked to an increased risk of Alzheimer's disease. These are common variants that appear more often in people who develop the condition than those who do not. "We know that a lot of the genes associated with Alzheimer's disease are those that regulate movement of cellular cargo to the trash, ie., the endolysosomal pathway," says Jayadev.

Searching through national databases, Jayadev and Brad Rolf, CGC, MS, genetic counselor at UW School of Medicine, chose a subset of 25 Alzheimer's risk variants that are specifically active in the endolysosomal pathway. They then developed a special scoring mechanism for research participants. The objective of this system, once a participant's DNA is analyzed, is to calculate a score for that individual based on the number of risk variants they carry; this is called their endosomal polygenic risk score. "A polygenic risk score allows you to take all of the different genetic changes a person has and puts that together into a single score that reflects how much risk those factors actually contribute," says Rolf. Different people carry their own unique combination and number of genetic risk variants and, thus, have distinct endosomal polygenic risk.

For their project, the researchers have selected eight ADRC research participants with a high-risk score, eight participants with a low-risk score, and eight unaffected controls, or people who did not have Alzheimer's disease in their lifetime. All 24 participants have undergone brain autopsy in the UW Precision Neuropathology Core. The researchers are now testing their hypothesis that brain cells from participants with high endosomal polygenic risk scores will show endolysosomal dysfunction and Alzheimer's disease pathology.

To study the biology of living brain cells, researchers in the Young Lab can generate human-induced pluripotent stem cells (iPSCs) from the study participants. This involves extracting cells from tissue in the outer lining of the brain during rapid brain autopsy, which occurs less than eight hours after death. Using a powerful genetic engineering technique, the team can cause these cells to revert to a developmental stem cell state. Because stem cells have the capability to grow into any type of human cell, researchers can chemically trigger them to grow into any type of mature brain cell, including microglia and neurons.

By observing and performing experiments on these patient-derived brain cells, the researchers hope to understand the properties of endolysosomal dysfunction in Alzheimer's disease at different levels of genetic risk. "I think this will be the first time that we can classify patients based on this specific cellular pathway. To me, that's really exciting," says Young. "It's like a new door opening for me in terms of how to treat the disease."

Young describes her vision for what will come out of this new research avenue as a precision medicine Alzheimer's clinic. In this future clinic, a patient developing cognitive symptoms could receive a polygenic risk score, which would tell doctors what type of Alzheimer's disease they likely have and what medication or intervention would be most effective. "In an ideal world, there'll be targeted therapies," Young says. "If you have a high endosomal polygenic risk score, you could be matched with a new drug developed specifically targeting that pathway. Because your risk lies in that system, you have a better chance of being responsive to that drug than another drug. But we have to find those drugs first."

Polygenic risk scores are not quite ready to use in the clinic to assess a patient's risk and treatment plan for Alzheimer's disease. Additionally, this tool may not provide accurate prediction of risk for everyone, as most of what the field knows about Alzheimer's genetics is based on studies of people with European ancestry. ADRC researchers expect that polygenic risk scores will become meaningful for more people as further studies focus on identifying genetic risk factors in diverse populations. •

This research project, 'Understanding the functional impact of cumulative genetic risk in Alzheimer's disease,' is supported by NIA grant 3RFIAG063540-01S1

Learn more:

ADRC Brain Bytes - Genetic Testing and Counseling for Alzheimer's with Brad Rolf, CGC, MS, UW Medicine (Video): https://youtu.be/4GFSBAqDj7s

Congratulations to the ADRC's Suman Jayadev for her appointment to the Department of Neurology Vice Chair of Research! "Suman Jayadev brings both basic science and clinical expertise. She bridges departments and has experience in the lab and with NIH funding. I'm very excited to see her contribution." - Thabele M. Leslie-Mazwi, MD, Professor and Chair, UW Department of Neurology at his introductory address to the Department of Neurology.

memoria.uw.edu

The UW Memory and Brain Wellness Center brings together a multidisciplinary team to develop models of clinical service, training, and research focused on culturally and linguistically proficient care aimed at reducing disparities in treatment outcome. We offer a webpage resource for LatinX and Spanish-speaking families and providers who serve Spanish-speaking populations. Visitors can find a list of local support opportunities, information about brain health, and culturally tailored videos to help family members navigate the experience of living with Alzheimer's disease or related conditions.

Visit http://memoria.uw.edu

You will find:

- **Conozca a Nuestro Equipo (Meet Our Team)**
- **Servicios Clinicos (Clinical Services)**
- **Información de Pérdida de Memoria (Memory Loss Information)**
- **Recursos de la Comunidad (Community Resources)**
- **Educación de Bienestar (Wellness Education)**
- **Oportunidades de Investigación (Research Opportunities)**
- **For Providers - Find Patient resources in Spanish**

¿Qué es el Alzheimer?

- El Alzheimer es la forma más común de demencia.
- Demencia es un término general que se aplica a la pérdida de memoria y otras habilidades cognitivas que interfieren con la vida cotidiana.
- El factor de riesgo conocido más importante es el aumento de la edad, y la mayoría de las personas con Alzheimer son mayores de 65 años.

Learn More

Questions?

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MEMORY LOSS: A GUIDE TO NEXT STEPS

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mbecker1@uw.edu or scan QR Code to the right:

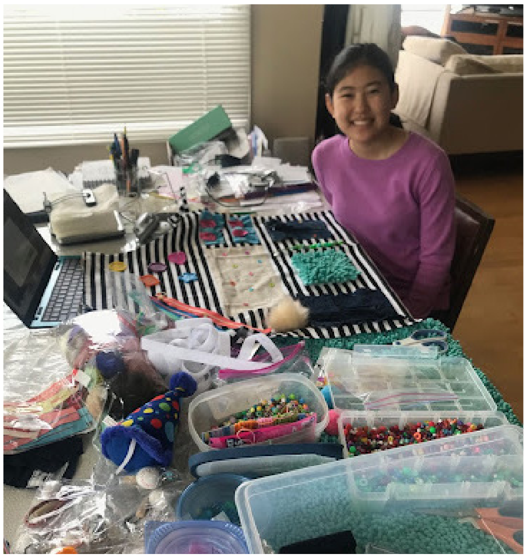
Homespun Comfort: My Fidget Apron Project

By Emi Takayama

I treasure my childhood memories of visiting my paternal grandmother, Megumi Takayama, in her nursing home near Tokyo Bay, Japan. There, we witnessed her enjoying piano music in the dining hall and occasionally taking wheelchair strolls. She had received her diagnosis of Alzheimer's disease at age 65, and during her late stages, I struggled with the lack of understanding of why she never spoke. Looking back, I wished I had spent more time with her, holding her hand and talking to her. Ultimately, I remain grateful for the tiny moments of grace that I shared with her.

Remembering her story propelled me to seek out volunteer opportunities within memory care centers. However, after the pandemic hit Washington, new state guidelines significantly impeded any community service I had envisioned. Fortunately, I soon discovered a project online posted by Gateway Hospice in Pittsburgh, PA, requesting "fidget aprons." Although I had never heard of these aprons before, I was excited to pursue an activity from home. Initially, a simple service project, fidget aprons have surprisingly uplifted my life and the lives of others.

My maternal grandmother and I found that fidget aprons are designed to provide sensory stimulation and other forms of comfort for people living with dementia. Fidget or activity aprons have unique sensory attachments to help calm the patients. For example, buttons and zippers offer tactile reminders of past clothing, while fuzzy accessories elicit playfulness and warmth.



Emi Takayama

Fidget aprons can be thought of as a form of sensory stimulation, which also includes touch therapy, music therapy, aromatherapy, horticultural activities, and more. Research shows that sensory stimulation can decrease anxiety for people living with dementia. According to the Canadian Association of Occupational Therapists, sensory stimulation works best with familiar objects and textures. On a fidget apron, you can fasten objects that carry personal significance for your loved one, such as key chains, buttons, baby socks, pieces of old fabric or pockets from favorite shirts. My hope is that fidget aprons can not only engage a person's senses, but also evoke pleasant memories from their past.

After researching, my grandmother and I decided to hand sew some aprons for Gateway Hospice and the UC Davis Hospice Program, where patients receive end-of-life care. We began by purchasing strong, sturdy fabric to create a blank apron and made several trips to craft stores and Goodwill for sensory attachments. In the design process, I had to consider safety for the people who will wear these aprons by ensuring that the objects attached would not easily break or fall off and become swallowing hazards. We quickly learned that items like tiny beads or inexpensive pom-poms may easily break or shed. After much trial and error, eventually, my grandmother and I produced over 50 aprons.

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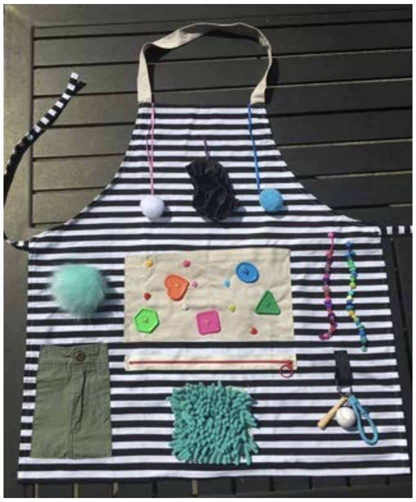
Covid-19 and public health regulations have had a devastating impact on hospice residents and faculty. Towards the start of the pandemic, Gateway Hospice Volunteer Coordinator Suzanne Ferguson noted, "People were dying sooner and there was more depression, more anxiety... People need contact, they need to be able to see people, they need to be able to touch people." I hoped that with my apron project, I could provide a small amount of human connection in this time of need.

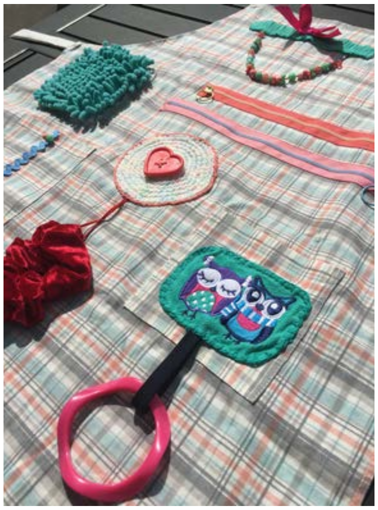
We were ecstatic to hear feedback from the staff at UC Davis about our donation of aprons. "The fidget aprons have been even more cherished during the pandemic when our in-person volunteer program has been closed due to COVID precautions," said Erin S. Bjork, UC Davis Hospice Volunteer Coordinator. Receiving feedback from both hospices has allowed me to further develop my fidget apron designs and prioritize not only physical stimulation but also visual. Ms. Ferguson pointed out that colors and aesthetics are important in addition to various textures.

Ms. Bjork added, "Our staff has been very thankful to have handmade gifts to deliver to the patients. The families are very appreciative of the gifts as well. Often, they aren't sure how to help calm their loved ones and keep their hands busy. The fidget aprons have been a welcome gift to support their loved ones. Families are so surprised and amazed that a teen would take the time to make the fidget aprons by hand for their loved ones." I now feel so blessed with the opportunity to participate in such a simple project that could impact so many people, including dementia patients, caretakers, and their families.

This year, I learned about the UW Memory and Brain Wellness Center clinic, and I decided to donate my remaining fidget aprons to patients and families who are interested in trying one out. "The donation of fidget aprons is a tremendous gift of time, effort and expertise. They are such a cool tool for our patients with dementia who need some meaningful activity and are such a beautiful outlet for their curiosity," said Elisabeth Lindley, certified nurse practitioner, UW MBWC Clinic. The clinic currently has a small number of aprons available for donation. If you are interested in reserving one, please contact gwanucha@uw.edu. •

Sources available in the online version of this article at: https://depts.washington.edu/mbwc/news/article/my-fidget-apron-project





MAKE YOUR OWN FIDGET APRONS!

You will need: 1.5 yards of cotton woven fabric, zipper and scrap fabrics, ribbon, trim, key rings, additional objects (see list below), and an apron sewing pattern (Recommended: A Sewing Pattern from Fishstick Designs - http://www.fishsticksdesigns.com/blog/wp-content/uploads/2013/07/FD_BusyHandsFidgetApron.pdf. You can also buy a blank, pre-made apron, or use one you already have, instead of following a sewing pattern.

Some tips:

Avoid small buttons or any tiny objects that patients could choke on.

High quality Pom-poms: We found cheap pom-poms but realized they were pretty easy to destroy and pick at, so instead we went with some better quality keychain pompoms that people usually attach to backpacks.

Sensory diverse materials: Sensory diverse materials (unique fabrics, bath mats, etc.). You can cut out squares of super interesting fabric and glue them down to the apron.

Keychains and Beaded chains: We also bought keychains and beaded chains that we sewed on, but I think you could instead attach keychains to the straps of the apron at the top.

Fuzzy socks: We ended up using a good amount of baby socks, which are very soft.

Dollar store items, Goodwill: We found some great materials at the dollar store and at Goodwill, such as loofahs and squishy keychains that had many different textures.

Visuals are important! Use nice colors that appeal to your loved one's senses.

Visit Emi Takayama's blog: https://www.alzadvocate.org

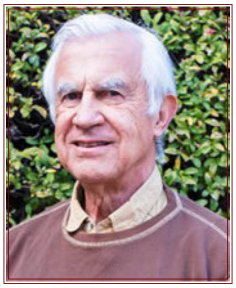
Indigenous perspectives on dementia and dementia-friendly communities

A dementia-friendly community is one in which people with memory loss and their loved ones are respected and included and can participate confidently in community life. One panel at the Memory and Brain Wellness Center's Collaborating for a Dementia-Friendly Washington: Expanding Possibilities Conference on September 14 explored Indigenous perspectives on dementia and dementia-friendly communities.

Panel moderator Ka`imi Sinclair, PhD, MPH (Western Cherokee), Associate Professor and Co-Director, WSU Institute for Research and Education to Advance Community Health, opened by first paying respect to our Coast Salish elders and welcoming three panelists who have decades of experience working in the field of Indigenous aging. They discussed the questions: **How is memory loss or dementia perceived or viewed among Indigenous people in general, in your experience? How are older Indigenous adults living with dementia woven into their communities, or not? What would an Indigenous dementia-friendly community look like? Have you seen any examples?**

Here are some takeaways from the panel!

Jordan P. Lewis, PhD, MSW (Aleut) Associate Director of the Memory Keepers Medical Discovery Team / Professor, Department of Family Medicine & Biobehavioral Health, University of Minnesota Medical School



Dave Baldridge (Cherokee Nation) Executive Director, Co-Founder, International Association for Indigenous Aging

Becky Bendixen, (Unangax) Tribal Program Specialist, Wisdom Warrior T-Trainer, Northwest Regional Council

>>> Different understandings of dementia and changing perceptions

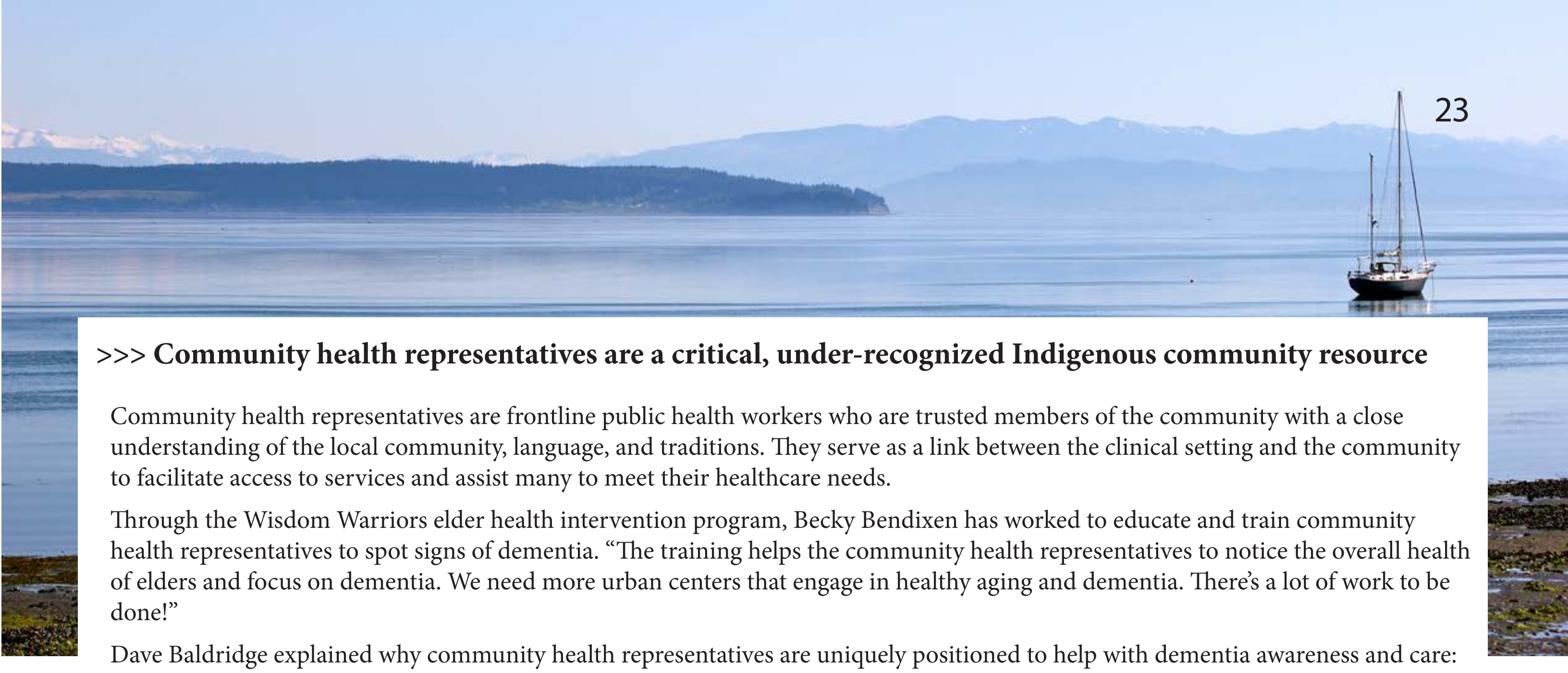
The panelists discussed a wide variety of understandings of dementia within Indigenous communities and families, and highlighted areas of unmet need. Jordan Lewis takes his knowledge from research studies in his group: "What we've learned from our research studies in cultural constructions of aging is that a lot of different families and culture groups have different understandings of dementia. Younger generations may be more aware of medical models of cognitive health and have a different perspective on how communities can work with people with dementia. Older adults often see dementia as a natural process of aging. If a person with dementia attributes it to bad behaviors when younger, kids can internalize it, or develop that the condition is contagious. I think the health care system would benefit from learning different cultural perspectives on dementia and integrating that into the health system."

> **"What I would like to see in a dementia-friendly community is that everyone be aware of what dementia is and not be afraid to offer help to older adults or younger adults affected by dementia."**
> - Dr. Jordan Lewis.

Becky Bendixen sees hopeful changes in her own community in Bellingham, WA: "I see confusion and anger about what is happening among Indigenous people who experience dementia. They may not speak of 'dementia', but will say 'crazy'. But, in the past few years, it's been changing, and I see more understanding that dementia is not a choice, it's real and it's a disease. I see tribal clinic and elder coordinators make a protective circle around the elders living with dementia. So, I think we are headed in right direction."

Dave Baldridge widened the focus to include the relationship between families and medical professionals: "Our nonprofit team conducted a national survey of Title VI Directors and Tribal Health Directors, and what we learned is that there is an enormous amount of denial around the condition. Concern for privacy is an important barrier to people being open to sharing. There are few programs on the ground sponsored by the tribes to help families struggling with dementia. The local medical community has been slow to respond to dementia-related issues and they are overwhelmed with Covid-19."

Read more: Lewis, Jordan P et al. "Making Sense of a Disease That Makes No Sense": Understanding Alzheimer's Disease and Related Disorders Among Caregivers and Providers Within Alaska Native Communities. *The Gerontologist*. Vol. 61,3 (2021): 363-373. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8023374/



>>> Community health representatives are a critical, under-recognized Indigenous community resource

Community health representatives are frontline public health workers who are trusted members of the community with a close understanding of the local community, language, and traditions. They serve as a link between the clinical setting and the community to facilitate access to services and assist many to meet their healthcare needs.

Through the Wisdom Warriors elder health intervention program, Becky Bendixen has worked to educate and train community health representatives to spot signs of dementia. "The training helps the community health representatives to notice the overall health of elders and focus on dementia. We need more urban centers that engage in healthy aging and dementia. There's a lot of work to be done!"

Dave Baldridge explained why community health representatives are uniquely positioned to help with dementia awareness and care: "Because dementia is behavioral in its expression, the community health representatives are most likely to see signs of dementia first. They step up to the plate and provide some outreach and services for their elders. Their ability to be involved with dementia issues varies with the tribe they work for, but I think community health representatives, with eyes on the ground, are an underrecognized resource and one we could be making more use of."

Read more:

- Resources for Community Health Representatives: http://depts.washington.edu/mbwc/adrc/page/community-health-representatives
- A Call to Action: Alaska's 10-Year Map to Address Alzheimer's and Related Dementia: https://alaskamentalhealthtrust.org/wp-content/uploads/2021/01/A-Call-To-Action-Alzheimers-Disease-Related-Dementia-10-Year-Map.pdf

>>> Examples of growing success in dementia-friendly community outreach

The panelists shared examples of what an Indigenous dementia-friendly community looks like. "An example of dementia-friendly community I've seen is a tribal nation here in Minnesota that has every 5th and 6th grade class take a dementia training class because they are becoming family caregivers for their grandparents at home," said Jordan Lewis. "They are trained to know basic behaviors, warning signs, how to help with things and not go home and be scared, and how to ask for help."

Lewis also mentioned that the Title VI Elder Nutrition Program can go beyond delivering home delivering meals to elders and also look out for basic warning signs of dementia and, if needed, alert the family or the Title VI office. "What I would like to see in a dementia-friendly community is that everyone be aware of what dementia is and not be afraid to offer help to older adults or younger adults affected by dementia."

Becky Bendixen gave advice on creating valuable community programs or support groups for elders living with memory loss: "Make it simple and easy and relevant to the culture we are dealing with. We do it using our food, language, our history, and our culture. We don't say we are going to "a chronic health self-management program", we say we are going to "a Wisdom Warrior meeting". Support group is not a fun word. What's another word for support group that doesn't make it sound like you need help?"

Highlighting examples of success, Dave Baldridge encouraged all those interested to check out Dementia Friendly Nevada, a community action group that is co-facilitated by Dr. Jennifer Carson, Director of the Dementia Engagement, Education and Research Program, University of Nevada Reno and Carla Eben, Director of Numaga Senior Services, Pyramid Lake Paiute Tribe: https://dementiafriendlynevada.org/communities/pyramidlake.

The panel also recommended exploring the Banner Alzheimer Institute's Native American Outreach Program, which offers many community and caregiver services and resources: https://www.banneralz.org/finding-support/native-american-outreach-program. •

View the recorded panel! https://youtu.be/0wr6QUOayk8

Photo: Deception Pass, WA. Image, Krystal Koop (Makah)

A Year in **Virtual** Garden Discovery Walks

In 2021, the UW Memory and Brain Wellness Center and Seattle Parks and Recreation decided to continue the virtual version of the Garden Discovery Walk program, as a way to connect the memory care community to nature and horticulture therapy during the pandemic. Peach Jack, horticultural therapist and MBWC intern, took the lead this year. She hosted and created the virtual tours of local gardens and the accompanying nature-inspired project designed for people to follow at home.

"I especially loved being able to tailor these walks to what was in season at the time of taking the photos," says Jack. "My intention was to link appropriate crafts to the walks using plant materials with simple instructions in order to bring nature into each person's home."

This program continues to be possible because of generous, ongoing support from Family Resource Home Care. We are thankful that they understand the value of bringing nature experiences and horticultural therapy to people who may not be able to regularly access the outdoors or group programs.

There is, of course, no easy replacement for being outside in a stimulating, beautiful garden or park. The goal of the virtual tours is to transport people into a nurturing, refreshing environment and to capture the sights and sounds along the way. The virtual tours and craft demonstrations offer unique benefits for people living with memory loss and their families. For example, the virtual program is easier to attend and presents no need for registration or a limit to the number of attendees.

Peach was able to film tours of gardens that we had never visited during the in-person Garden Discovery Walk program. New tours this year included a native forest on the Oregon coast (June), Lake Wilderness Arboretum and Western Azalea collection garden (July), Kruckeberg Botanic Garden (August), the Bellevue Urban Garden (October), as well as a long-distance visit to the Lady Bird Johnson Wildflower Center in Austin, Texas (May). The variety of visits to these gardens made it possible for the community to explore places they may never have been, as well as revisiting some where they have memories of sensory experiences.

"My hope is that the memory care community may be inspired to visit some of these locations," says Jack. "And it is with great joy that I anticipate the resuming of in-person garden and horticultural therapy experiences with the opening of Maude's Garden at the Memory Hub in March of 2022." Read more about the Memory Hub and Maude's garden on page 8!

* * *

View the Virtual Garden Discovery Walk video playlist:

https://tinyurl.com/3xyrzn2v

Thank you to:

Family resource home care

Check out some of our favorites!

In January, we explored the sights, sounds, and aromas at the Joseph A. Witt Winter Garden of the Washington Park Arboretum. Community member Patricia Valentine joins for this walk. The project reveals new ways to use watercolors to capture the colors and textures of the winter garden.

Peach Jack leads a calm, mindful February walk through the Kubota Garden, a landscape in South Seattle that blends Japanese garden concepts with native Northwest plants. Then it's time to create landscapes with tissue paper!

September brought us to the luscious botanical scenery of Dunn Gardens in Shoreline, WA. We were lucky to have Dunn Gardens Executive Director Carolyn Cox with us to share interesting history about this unique landscape. The project explores uses for the lavender plant in your home.

October's walk explored the inspiring tBUG: The Bellevue Urban Garden, a volunteer-run farm in the Lake Hills Greenbelt that inspires and educates a diverse community on ways to grow nutritious food. We met tBUG Founder Mayvin Chisebuka from Zambia who is driven to fight hunger through gardening. We also learned from volunteers from Fare Start harvest weekly. The accompanying craft project guides viewers through growing their own lemon tree.

Group Haiku

by the Gathering Place

These poems were written by members of the Gathering Place, a weekly enrichment group for people living with dementia, held at the Greenwood Senior Center. The group collectively wrote these haikus to describe some of their most salient experiences receiving medical care and the challenging emotions that arose for them through their experiences living with dementia.

A looming white coat,
“You can still do many things” -
I drive home crying.

Dementia they say
and the world shrinks away.
Who can take you home?

But can I still work?
My former life is changed.
Footsteps hurry by.

Shiny white clean floors.
How do I tell my friends
Or my family?

You can no longer drive
Anger, disbelief, fear.
See you in three months.

PNA
Community Begins Here
Greenwood Senior Center

Team MBWC Walked in Support of Alzheimer's Research, Loved Ones

On Saturday October 2, 2021, the Alzheimer's Association WA State Chapter hosted the Walk to End Alzheimer's Disease. The Memory and Brain Wellness Center Team gathered at the International Fountain, donned hats, purple necklaces, and promise flowers, for the mile-long walk around Seattle Center. Cheered on by Alzheimer's Association staff and onlookers, we walked in support of all those affected by Alzheimer's and related disorders, including loved ones. We raised $200 in donations for Alzheimer's care, support, and research. According to the Alzheimer's Association, the local walk events brought in nearly $1.5 million, raising critical funds and awareness to support the cause!

Our team of walkers that day included MBWC neuropsychologist Kristoffer Rhoads, PhD and member of the Alzheimer's Association WA Board of Directors; MBWC neuropsychologist Carolyn Parsey, PhD; ADRC research coordinator Alicia Adams, and Center communications specialist Genevieve Wanucha. It was Adams' 5th Walk to End Alzheimer's! We had the pleasure of meeting Alzheimer's Association staff members Kelsey McGlynn, Constituent Relations Associate and Hailey Adair, Office Administrator, who said that Seattle Center has provided her new favorite location for a Walk to End Alzheimer's, with the wide open grassy lawn for vendors and attendees and flowing fountain. We are looking forward to participating again next year!

Alzheimer's Association Advocacy Day: February 9, 2022

Washington State residents are invited to join the Alzheimer's Association for the 2022 Advocacy Day on on Feb. 9, 2022. Meet with your elected officials and ask them to support Alzheimer's Association legislative priorities. This year, meetings will take place virtually, so you can join from wherever you are. Together, we can make a difference.

Learn more and register at alzwa.org/advocacyday.

Read about community member Kevin Kvarda's advocacy projects:

Wicked Diseases, Advocacy, and Gifts, Oh My! My Journey from Disease into Advocacy powered by P.R.I.S.M and P.U.S.H:

depts.washington.edu/mbwc/news/article/journey-from-disease-into-advocacy

The Memory Loss Compass Rose: Towards a New Identity, Hope, and Strength Post-Diagnosis: Chapter 2 of My Journey from Disease into Advocacy by Kevin Kvarda:

depts.washington.edu/mbwc/news/article/memory-loss-compass-rose

Enrolling Research Studies

AHEAD STUDY

The AHEAD Study is testing whether an investigational treatment can lower people's risk of memory loss due to Alzheimer's disease. The study is funded by the National Institutes of Health, in partnership with the pharmaceutical company Eisai. It is being conducted by the NIH-funded Alzheimer's Clinical Trial Consortium (ACTC), a network of leading academic medical centers.

You may be able to join if:

- you are healthy adults ages 55-80.
- you have not been diagnosed with Alzheimer's disease or another dementia.
- you have a study partner, either a close relative or friend, who will participate in one study visit per year.
- you have elevated or intermediate levels of amyloid in their brain, found by imaging as part of the study.

Contact: Darla Chapman, ARNP at 206-744-9337 or darlac@uw.edu.

Website: www.aheadstudy.org

GREEN MEMORY: GREen Valley 971 EvaluatioN Memory

The GREEN MEMORY Study is looking at an investigational medication, taken by mouth, for people with mild to moderate Alzheimer's disease. The investigational medication is designed to restore the natural balance of bacteria in the gut. There are certain bacteria that are thought to cause inflammation in the brain and nerves, possibly contributing to Alzheimer's disease. The purpose of this study is to evaluate the safety, tolerability and efficacy of GV-971 in mild to moderate Alzheimer's disease.

You may be eligible if:

- you are between 50 and 85 years of age
- you are experiencing memory issues or have been diagnosed with mild to moderate Alzheimer's disease.
- you have a study partner who knows you well, is with you three or more days a week, and can come to all study-related visits.

Contact: Azma Parhin, MD, Research Coordinator, UW ADRC at 206-897-6350 or azmap@uw.edu

Website: www.greenmemoryalzstudy.com

MAP

Metformin in Alzheimer's dementia Prevention

MAP is a research study looking at whether the drug metformin can help prevent memory decline for people with mild memory concerns. It is a randomized study in which you will take either metformin (Glucophage® XR) or a placebo.

You may be able to join if:

- you are 55-90 years old
- you or your loved ones have noticed some changes in your memory, and
- you are not already being treated for diabetes or dementia

You will receive some of your blood test results. We can also share these results with your healthcare provider. Your participation may improve the prevention of dementia for future generations. If you decide to join, you will be compensated for your time

Contact: Hanson Research Team : (206) 744-1851 or (206) 897-5393 or hansonlab@uw.edu.

Website: www.iths.org/participate/metformin-in-alzheimers-dementia-prevention-map/

The Remote Cog Study

Black Americans often miss out on early care that can help with memory and mental health changes. We hope to learn how to spot these changes earlier in Black Americans.

Researchers at the VA Puget Sound Hospital in Seattle are enrolling Black Americans who are age 65+, concerned about their memory, and interested in a 10-week research study from the comfort of their own homes that includes:

- **Answering health-related questions using paper, a telephone, and a mobile device**
- **Using several devices at home, including a wristwatch, thermometer, and blood pressure monitor**
- **Providing a blood sample**

Contact: the Remote Cog study team at 206-277-1379

For a complete listing of all enrolling studies, visit the UW ADRC's Clinical Trials & Studies page:
depts.washington.edu/mbwc/adrc/page/clinical-trials

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