• Spring 2023

# DIMENSIONS

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

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- The Power of Connection in Dementia Care

Hello readers! The UW ADRC and the UW Memory and Brain Wellness Center are pleased to bring you the Spring 2023 edition of Dimensions!

We are nearing the first anniversary of the opening of the Memory Hub, a nationally unique community center on Seattle's First Hill, in partnership with the Frye Art Museum. We are proud of our team and many partners and collaborators for creating a vibrant place for dementia-friendly community, collaboration, and statewide impact. Drop by during our new public open hours to enjoy our library and resource room, memory garden, art gallery, free 30-min Memory Navigator appointments and Tech Lab demos. You can learn more about these opportunities in this issue.

With many new staff and clinical trials, the Alzheimer's Disease Research Center is equipped for another year of fantastic contribution to the efforts to solve this disease. At the same time, we are saddened to share the news that the ADRC's founding director, UW Professor Emeritus George M. Martin, MD, passed away on December 17 at the age of 95. We also lost Ka'imi Sinclair, PhD, MPH, a key member of our ADRC Outreach, Recruitment and Engagement Core, who devoted her career at Washington State University to brain health equity in indigenous communities. Join us in remembering the legacies of these dear community members. Finally, we also mourn the loss of K. Warner Schaie, PhD, UW affiliate professor of psychiatry and behavioral sciences and Evan Pugh Professor Emeritus of Human Development and Psychology at Pennsylvania State University, who founded the visionary Seattle Longitudinal Study of cognitive aging.

In these pages, you will 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. MBWC geriatrician Angela Hanson, MD shares her key takeaways from the 2022 Clinical Trials on Alzheimer's Disease conference, a meeting focused entirely on Alzheimer's disease therapeutic trials, with special attention to lecanumab. This diverse issue also highlights new findings about sleep and brain health; the artwork of a researcher who is inspired by the beauty she sees in dissected human brain tissue; the perspective of a caregiver who is sharing her mother's story to help and inspire others; and much more.

We hope you take away a sense of our gratitude toward all who contribute to making this work possible. At the end of this issue, please find our acknowledgement of the generous donors who have made it possible for us to move faster in research and reach further into the community than ever before. Your interest and contributions make a big difference and help us advance the day when threats to memory and brain health will be detected and prevented as the standard of care. Happy reading!

Thomas Grabowski, MD UW ADRC Director

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Kimiko Domoto-Reilly, MD Outreach, Recruitment and Engagement Core Co-Lead



Genevieve Wanucha, MS Dimensions Editor

#### UW ADRC Leadership

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Alzheimer's Disease **Research Center** 

**UW** Medicine



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The Memory Hub





**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: <u>uwadrc.org</u> MBWC: <u>uwmemoryandbrain.org</u> The Memory Hub: <u>thememoryhub.org</u> Facebook: <u>facebook.com/UWMBWC</u> Twitter: <u>twitter.com/MemoryBrain\_UW</u>

**Cover Art by** Barbara Ann Clinkston (1931-2022) *Untitled, 1980s.* Learn more on page 22.

#### **RESEARCH HIGHLIGHTS**

UWADRC.ORG

### **DISCOVERIES MADE POSSIBLE BY YO**

#### Neuropsychology

Mukherjee S, et al. Cognitive domain harmonization and co-calibration in studies of older adults. *Neuropsychology*, 2022. Shubhabrata Mukjerjee, Seo-Eun Choi, Michael L. Lee, Phoebe Scollard, Emily H. Trittschuh, Jesse Mez, Andrew J. Saykin, Laura E. Gibbons, R. Elizabeth Sanders, Andrew F. Zaman, Merilee A. Teylan, Walter A. Kukull, Lisa L. Barnes, David A. Bennett, Andrea Z. Lacroix, Eric B. Larson, Michael Cuccaro, Shannon Mercado, Logan Dumitrescu, Timothy J. Hohman, Paul K. Crane

In large, long-running studies of older adults, such as the Adult Changes in Thought Study (participants = 5,546) and the Rush Memory and Aging Project (participants = 2,163), participants attend regular research visits over time and undergo different tests, including tests of cognition, or thinking and memory. These studies generate loads of data for researchers to use to find associations between lifestyle factors or genetics with late life cognitive functioning and impairment. However, each study uses different tests to measure cognition and its changes over time. This situation makes it complicated for a researcher to directly compare the results of individual cognitive tests when using data pooled from multiple studies.

In what Paul Crane, MD, MPH, a professor of medicine at the UW School of Medicine, calls a 'Hello World" methods paper, a UW-led team shares the results of a major effort to make it easier for researchers to leverage data from multiple studies of older adults. They have succeeded in taking the cognitive scores across 10 different studies and calibrating them according to the same metric. "What that means," says Crane, "is that the scores from each study are now directly comparable to one another; they mean the same thing about a participant's performance. So, if a person in Study A had been evaluated and studied in Study B, this person would be expected to have the same score."

These calibrated memory scores for 10 different study datasets have many benefits to the Alzheimer's field. A researcher can focus on their burning scientific question at hand instead of statistical manipulation of datasets. "Our science is really benefiting a lot from the recent moves towards data sharing and data availability," says Crane. "Our group is doing the work to make it so that those shared data are amenable to quick scientific analyses of relationships between cognition and whatever else is of interest, across multiple different datasets—and without anyone else needing to worry about the details that we worry about."

Crane thinks that this data harmonization approach will lead to more confidence in scientific results in the Alzheimer's field, through the ability to ensure that an association found in one dataset can also be found in multiple studies of cognitive aging. Now, the team is working to generate these co-calibrated memory scores from the UW ADRC Clinical Core participants, to make this dataset easily comparable with that of other longitudinal studies and make these cognitive data even more useful.

This effort is part of the NIH-funded Alzheimer's Disease Sequencing Project Phenotype Harmonization Consortium, a larger collaboration of four institutions to pool data from more than 30 research cohorts using data harmonization methods. The types of data include cognitive performance, genetics, neuroimaging, biomarker data and autopsy neuropathology data. The goal is to produce a large-scale, racially diverse, standardized set of transparently defined data that will open new windows into the genetic basis of Alzheimer's disease and resiliency.

Caregiving

Zaslavsky et al. Virtual Intervention for Caregivers of Persons With Lewy Body Dementia: Pilot Quasi-Experimental Single-Arm Study *JMIR Form Res*, 2022. Oleg Zaslavsky, Jasmine Kaneshiro, Frances Chu, Andrew Teng, Kimiko Domoto-Reilly, Annie Chen

A team of UW School of Nursing and UW Medicine researchers have completed a pilot evaluation of a digital intervention designed to help caregivers of people with Lewy body dementia address challenges they have experienced, with the goal of promoting resilience and reducing distress in this population.

The Lewy body dementias, a term referring to both dementia with Lewy bodies and Parkinson's disease dementia, are the second most common type of dementia in older adults. These are complex disorders because patients may develop disruptive behaviors and sleep problems that make caregiving challenging. Compared to other types of dementias, caregivers of people with Lewy body dementia report higher stress and more severe depressive symptoms.

With help from the ADRC, the team recruited 15 family caregivers of people with Lewy body dementia to participate in the study, Virtual Online Communities for Aging Life Experience-Lewy Body Dementia (VOCALE-LBD). The study offers an 8-week webbased intervention that uses a digital discussion platform and involves moderation, peer-to-peer support, education and training, and problem-solving skill practice.

In the study, many caregivers reported that participation in VOCALE-LBD helped them better understand the disease, feel more confident in dealing with difficult behaviors, and improve their ability to care for their loved one. If validated in future studies, the intervention could provide an accessible resource for caregivers to engage in moderated online discussions with peers at their own homes. The team is now looking for informal caregivers of people with Lewy body dementia to participate in virtual focus groups and usability testing sessions. If you are interested, please visit <a href="https://sites.uw.edu/vocale/lbd/">https://sites.uw.edu/vocale/lbd/</a>.



Shea D et al. SOBA: Development and testing of a soluble oligomer binding assay for detection of amyloidogenic toxic oligomers. *Proc Natl Acad Sci U S A*, 2022. Dylan Shea, Elizabeth Colasurdo, Alec Smith, Courtnie Paschall, Suman Jayadev, C. Dirk Keene, Douglas Galasko, Andrew Ko, Ge Li, Elaine Peskind, Valerie Daggett

In the earliest stages of Alzheimer's disease, the brain forms toxic aggregates, called oligomers, of the protein amyloid beta. These oligomers can start to form more than a decade before symptoms appear and before other known disease markers form. The ability to detect these oligomers would permit early disease diagnosis. This would make strategies to intervene before irreparable brain damage occurs possible.

A research team led by Valerie Daggett, PhD, professor of bioengineering in the UW Molecular Engineering & Sciences Institute, in collaboration with ADRC researchers, developed a method to detect toxic amyloid beta oligomers in patients' blood. They tested the assay, called the soluble oligomer binding assay (SOBA), on nearly 400 banked human blood plasma samples from 310 ADRC research participants. At the time the blood samples had been taken, these people were recorded as having no cognitive impairment (controls), mild cognitive impairment, Alzheimer's disease, or other forms of cognitive impairment.

SOBA detected toxic oligomers in 52 out of 53 people with Alzheimer's disease or mild cognitive impairment. As expected, the blood test did not detect oligomers in most of the samples of control subjects who had no cognitive impairment. However, SOBA detected oligomers in 11 controls, and 10 of these positive samples came from people who later developed mild cognitive impairment. This finding shows that the SOBA test detected the toxic oligomers of amyloid beta before Alzheimer's symptoms appeared. The researchers suggest that SOBA could form the basis for early diagnostic tests.

"We believe that SOBA could aid in identifying individuals at risk or incubating the disease," Daggett says, "as well as serve as a readout of therapeutic efficacy to aid in development of early treatments for Alzheimer's disease." Daggett has a startup company working on this promising platform for early diagnosis and treatment of Alzheimer's. Hear her present about the technology and collaborations driving this work at the 2022 UW Engineering Lecture Series: <u>https://youtu.be/G3r-FDUblB8</u>

Adapted from NIH Research Matters

Genetics

### Course MM et al. Aberrant splicing of PSEN2, but not PSEN1, in individuals with sporadic Alzheimer's disease. *Brain*, 2022. Meredith Course, Kathryn Gudsnuk, C. Dirk Keene, Thomas Bird, Suman Jayadev, and Paul N. Valdmanis

Pathogenic gene variants in PSEN1 and PSEN2 are rare causes of familial Alzheimer's disease. But UW researchers have reason to think that these genes also hold clues to cases of the more common late-onset 'sporadic' Alzheimer's disease. Recent work from a UW team, including UW ADRC researchers, uncovered evidence that age-related changes in the way PSEN2 or generates transcripts (instructions of making proteins) may be involved in sporadic Alzheimer's risk in the general population.

The team has since worked to identify these flawed recipes for proteins in Alzheimer's pathology. "This project is exciting," says study author Paul Valdmanis, assistant professor of medical genetics in the UW Department of Medicine, because "we could provide insight into why individuals develop Alzheimer's disease without a family history of disease."

In a new study published in Brain, the team characterized novel PSEN1 and PSEN2 transcripts in samples from cases of familial (carrying known PSEN1 and PSEN2 variants) and cases of sporadic Alzheimer's disease from the UW ADRC and healthy controls from the ACT Study. They leveraged PacBio Iso-Seq—a third-generation sequencing method for obtaining long reads of transcripts.

The team found certain abnormal splice products of PSEN2 only in late-onset sporadic Alzheimer's disease samples. This finding suggests that genetic transcript differences in PSEN2 may play a role in Alzheimer's disease in the general population.

"What really surprised us was that individuals with pathogenic variants in PSEN1 or PSEN2 did not share the same high level of abnormal splice products in PSEN2 as individuals with late-onset sporadic disease. We reason that this is likely because these familial cases already have a genetic hit that causes Alzheimer's disease."

The researchers see this research as a possible first step in discovering ways to preserve genetic function as a possible future treatment. This work was supported, in part, by a UW ADRC development project grant awarded to Meredith Course, PhD and by the UW ADRC Neuropathology Core.

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.

Find more Discoveries Made Possible By You on uwadrc.org at:

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

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)** 

Developing the Privately Owned Companion Dog as a Model for Alzheimers Disease, NIA R24, **Matt Kaeberlein, C. Dirk Keene (PIs)** 

### Allen Institute/UW Laboratory Medicine and Pathology

A platform for cell type-level transcriptomic, epigenomic and spatial interrogation of Alzheimer's disease NIA U19, **Ed Lein**, **C. Dirk Keene**, **Jennie Leigh Close**, **Michael Hawrylycz**, **Rebecca Hodge (PIs)** 

Novel platform for research brain banking and characterization using integrated traditional and quantitative analyses to promote precision neuropathology of Alzheimer's disease, NIA U19, **C. Dirk Keene (PI)** 

#### Department of Neurology

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

#### Department of Psychiatric & Behavioral Sciences

Tai Chi Practice and Sleep-Active Glymphatic Function, NIA R61, Gail Li, Jeff Iliff (PIs)

Use of wearable sensors to improve the early diagnosis of DLB. NIA, R33, **Debby Tsuang (PI)** 

UW Alzheimer's Disease Training Program (ADTP) Neurobehavior, Neuropathology, and Risk Factors in Alzheimer's Disease, NIA T32, **Elaine Peskind, Brian Kraemer** (**PIs**)

Defining the Role of Post-TBI Sleep Disruption in the Development of CTE and Alzheimer's Disease-Related Neuropathology, NIA R01, **Elaine Peskind (PI)** 

#### **Division of Medical Genetics**

Novel approaches to identify tandem repeat expansions in neurodegenerative disease NIH R01 Paul Valdmanis (PI)

Interrogating regulatory noncoding RNAs in Alzheimer's disease synapses - Alzheimer's Association Research Grant. **Paul Valdmanis (PI)** 

#### **School of Public Health**

Transition to Aging Award for my project titled "Integrating Polygenic Risk and Environmental Exposures to Uncover Biological Mechanisms Underlying Dementia in a Diverse Cohort. NIA F99/K00, **Diane Xue, ADTP predoctoral fellow** (**PI**)

#### **Division of Gerontology & Geriatric Medicine**

NEW GRANTS AND FUNDING

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

Western Medical Research Conference Student Subspecialty Award, October 2022, **Van Nguyen** (Summer Medical Student with Elizabeth Rhea)

Mechanisms of TDP-43 neurotoxicity in Alzheimer's disease. VA Merit Award, **Nicole Liachko (PI)** 

Drivers of vulnerability to Alzheimer's disease neuropathological changes, BrightFocus Foundation, **Nicole Liachko (PI)** 

Developing Neuroprotective Strategies for Tau and TDP-43 Proteinopathy in FTLD, NIH R01, **Brian Kraemer (PI)** 

Protection from pathological tau by activation of the ER unfolded protein response, NIA R01, **Brian Kraemer (PI)** 

APOE genotype effects on triglycerides and blood flow in the human brain, NIA R01, **Angela Hanson (PI)** 

#### School of Social Work/ UW Clinical Informatics Research Group

a2 Pilot Award of the Artificial Intelligence and Technology Collaboratories for Aging Research program, NIA, **Clara Berridge (PI)** 

### Kaiser Permanente Research Institution/ UW School of Medicine

Cognitively Defined Alzheimer's Subgroups: Natural history, neuropathology, and life course ramifications, NIA U19, **Paul Crane (PI)** 

Adult Changes in Thought Research Program, NIA U19, **Paul Crane (PI), Andrea LaCroix, Rita Mangione-Smith** 

#### Washington State University (ADRC Collaborator)

Resilience, cultural alignment, and social support in brain aging: Data from the Strong Heart Study, NIA R01, **Astrid Suchy-Dicey (PI)** 

Incident Vascular Brain Injury, Probable Alzheimer's Disease, and Cognitive Change in Elderly American Indians, NIA K01, **Astrid Suchy-Dicey (PI)** 

## Congrats to Angela Hanson, MD, for receiving the MSTAR Best Research Mentor Award!

Sponsored by the National Institute on Aging, the MSTAR program encourages medical students to consider a career in academic geriatrics by <u>awarding short-term scholarships.</u>



Angela Hanson, MD

Late in 2022, I had the pleasure of Alzheimer's Disease meeting (CTAD) in San Francisco. The highlight of the conference was the announcement that lecanemab slowed cognitive decline in a phase 3 trial run by Esai. This drug is an antibody therapy that clears away amyloid plaques, a hallmark pathology in Alzheimer's disease.

#### Anti-Amyloid Therapies

The clinical benefit of lecanemab in symptomatic patients is real and significant but small. The Clinical Dementia Rating Scale, used to measure the impact of the drug, showed a 27% slowing of cognitive decline. But how important is the this slowing of progression seen with lecanemab? That slowing is actually less than one half of a point on an 18-point scale. However, this small effect could add up to meaningful benefit over a long time of taking the drug. Or, it may be helpful if it prevents important declines early enough in the disease.

One January 3, 2023, the FDA announced that they granted accelerated approval for lecanemab, aka Leqembi for early Alzheimer's disease, and we are still waiting to hear whether Medicare will cover this medication. This medication will be expensive and complex to administer, as it is an intravenous infusion and requires careful monitoring and brain MRI scans at various times throughout the treatment.

We also learned at the CTAD meeting that gantenerumab, another anti-amyloid therapy, did not meet clinical endpoints compared to placebo. This drug also showed a lower-than-expected reduction in brain amyloid at the end of the trial.

Overall, I would say the meeting atmosphere was that of cautious optimism.



Angela Hanson, MD, a MBWC geriatric physician and faculty member in the UW School of Medicine, reports on what she learned at the 2022 Clinical Trials on Alzheimer's Disease meeting (CTAD) in San Francisco. She reports back on the latest news in anti-amyloid therapies and the landscape of future approaches to treating and preventing Alzheimer's disease.

We were all very glad to hear that for the first time, one of these anti-amyloid therapies seemed to both reduce plaques and definitively improve outcomes that matter to patients, compared to the placebo group. But my caution comes with the knowledge that the medication is still quite expensive. Side effects can include brain bleeding, so we must monitor patients with regular MRIs. And there are still important unanswered questions about the anti-amyloid therapies. For example, how long do patients need to stay on the medication?

#### **Combination Therapies**

"It is past time to test combination therapies," stated a CTAD keynote speaker, Dr. Suzanne Craft, PhD, professor of gerontology and geriatric medicine at Wake Forest University and my former mentor. It may be that we have to try multiple things at once and start very early, to halt or prevent the progression of amyloid and tau pathology.

One example of this approach is the "MET-FINGER" study. This study will combine four prevention components, including physical exercise, diet, brain training, and health checks with a potentially preventative drug called metformin to see if this combination reduces "the risk of dementia and improves health and independence among older adults."

The need for combination therapies means we need to get smarter and more savvy about how we conduct clinical trials, instead of just testing one intervention at time. We may learn how early we need to start treating amyloid in the brain with the AHEAD study, which involves administering lecanemab to people at risk for developing Alzheimer's but who do not yet have symptoms.

#### Prazosin for Later Stage Dementia

The ADRC's Dr. Elaine Peskind, MD, professor of psychiatry and behavioral sciences at UW Medicine, presented work about using Prazosin in patients with dementia-related agitation. Because of challenges conducting a study in a nursing home during the pandemic, the team did not meet their target number for enrollment. However, the data showed that many people on Prazosin markedly improved in their agitation score. The drug was well tolerated without any increase in falls. It was good to hear that there are some promising medications being actively studied for this important issue.

I was also interested to hear about therapies "in the pipeline". These are compounds that either work in animal models or that have very early data in humans (in phase 1 clinical studies). These drugs have biological targets, including the Alzheimer's-related tau protein, the APOE risk factor for late-onset Alzheimer's, or brain insulin pathways, just to name a few. The hope is that if these therapies work in larger studies, they can be added alongside medications like lecanemab to help prevent or treat Alzheimer's before it has a chance to cause symptoms. • *Angela Hanson, MD* 

**Reference:** Aisen PS, Vellas B. We Have Turned the Corner. *The Journal of Prevention of Alzheimer's Disease*, 2022.

**On-Site Resources** 

**NEW open hours:** Tuesday, Wednesday, and Thursday 9 a.m. – 3 p.m.



Drop in during open hours to enjoy these resources. View our online calendar to sign up for other programs and events!

www.thememoryhub.org

#### The Memory Hub

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



The Memory Hub's **Library and Resource room** offers a variety of books and educational materials related to living with memory loss and caregiving, with titles such as *Creative Care: A Revolutionary Approach to Dementia Care and Elder Care* and *Speaking Dementia: Making Sense of it All.* We thank the Seattle Public Library Foundation for a generous donation of books. View the library catalog under the Resources tab on the Memory Hub website: www.thememoryhub.org.



**The Frame of Mind exhibit** at the Memory Hub's art gallery features art created by people living with memory loss. The paintings currently on display were created by participants in the Elderwise Day Program, which provides art and social engagement for adults living with memory loss. Using a wet-on-wet watercolor technique, Elderwise participants find freedom to play with color and explore new ways to express the essence of who they are. View exhibit online: www.thememoryhub.org/exhibit



The Memory Navigator program features free 30-minute appointments with an Alzheimer's Association care consultant to explore community resources and to address your questions about living with memory loss or caregiving. Learn more: www.thememoryhub.org/page/memory-navigator



Maude's Garden, the first public memory garden in Washington State, offers respite, social connection, and nature engagement to people living with dementia, caregivers, and the wider community. The garden is designed to be accessible with a sensory focus on plants and other features to touch, taste, feel, view, and hear. Learn more: www.thememoryhub.org/garden



**The Tech Lab** offers free consults on Tuesdays to discover ways that technology and apps can promote independence and health. Dr. Carolyn Parsey of the Memory and Brain Wellness Center will answer questions about your current devices (cellphones, tablets, laptops, etc.) or devices you are considering purchasing. Learn more, find resources, and book a consult: www.thememoryhub.org/page/tech-tuesdays

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Take an audio tour of the Memory Hub with KUOW's Soundside podcast!



A Seattle hub where people with memory loss can stop by







It's like when you jump on a trampoline and a second person jumps with you and you go much higher. The collaboration is palpable. It feels so supportive and it supports me in wanting to support others. There is an attractive force field here that brings volunteers of all kinds.

-Sandy Sabersky, Elderwise, on working at the Memory Hub

The Memory Hub is a collaborative community center on Seattle's First Hill for people with memory loss, their families, and all who support a dementia-friendly community.

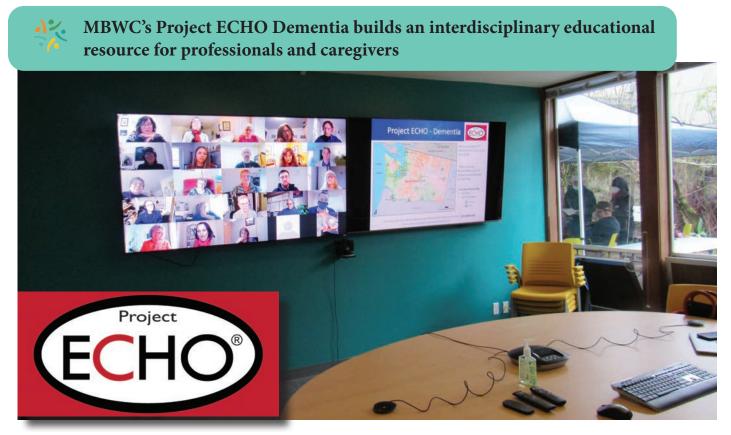
Since the Grand Opening in March 2022, the Memory Hub space has come to life with the launch of a variety of programs offering resources, music, art, nature engagement, and joyful opportunities for connection and learning.

"It's been so exciting to see the Memory Hub take off," said Memory Hub Director Marigrace Becker, MSW. "With a team of amazing mission-aligned organizations under one roof, we're discovering new ways to collaborate every day and are together becoming the vibrant community space we'd always envisioned!"

The Memory Hub brings together UW Memory and Brain Wellness Center (MBWC), the Frye Art Museum, the Alzheimer's Association, Elderwise, and Full Life Care. Read on as our collaborators share updates and reflect on the growth at the Memory Hub!



Pictured: Memory Hub Front Desk Volunteer Julie Pusztai and Tegenu Negi of Full Life Care



# The Memory Hub includes a permanent space dedicated to the Memory and Brain Wellness Center's Project ECHO Dementia. ECHO Dementia is a learning model in which front-line care providers from around WA State meet in a web-based virtual conference room with an interdisciplinary panel of experts in memory loss and dementia.

"We are enormously grateful for the participants who continue to show up and engage in deep discussion around issues related to dementia detection, diagnosis, and support,' says Allyson Schrier, program manager for ECHO Dementia. "It is not easy for frontline care providers to take the time to make this a priority. We are equally grateful to the amazing people who make up our Memory Hub team. The project's success lies in large part to their continued dedication. And we are grateful for the amazing cast of speakers whose presentations raise the caliber of learning to such a high level."

Over 55 recorded didactic lectures are available on the Project ECHO Dementia webpage. These lectures are a source of accessible information about the latest clinical knowledge about dementia, treatment, and available support and resources. Recent sessions include 'Fall Prevention for People with Dementia', 'Assessing and Treating Pain in People Living with Dementia', and 'Diet: A Solution Focused Exploration about How to Help People Switch to Healthier Options.' In 2022, a family care partner joined the ECHO Dementia Memory Hub team to lend a much needed and welcomed perspective to the discussions.

In 2022, ECHO Dementia leaders—Kristoffer Rhoads, PhD, a MBWC neuropsychologist and associate professor of neurology at teh UW School of Medicine and Nancy Isenberg, a neurologist at Swedish Neuroscience Institute and clinical associate professor of neurology at the UW School of Medicine—co-led the Providence Alaska ECHO Dementia Clinic, a 10-session ECHO program in Alaska in conjunction with Mountain-Pacific Quality Health. Powered by the Providence Age Friendly Innovation \$100,000 grant (awarded to Isenberg), this effort has led to continued community building in Alaska and potential for continued ECHO Dementia programming in Alaska in 2023 and beyond. In 2023, they will present about Project ECHO Dementia at the META ECHO conference in Albuquerque, New Mexico. The team aims to continue spreading their reach geographically to include healthcare providers from more rural and underserved populations. •





#### MBWC Launches Dementia Friends at the Memory Hub



Dementia Friends is a public awareness anti-stigma program that trains individuals on how to give an hour-long educational talk to their community about what is dementia and how to help their neighbors, friends, and family members with dementia.

In fall of 2022, the Memory and Brain Wellness Center launched Dementia Friends Washington at the Memory Hub, along with a website and social media. To date, Dementia Friends Washington has held two information sessions with 10 more planned.

"We are excited about the continued connections and opportunities to increase engagement and awareness about dementia through the Dementia Friends program in Washington State," says Emily Meeks, program manager for Dementia Friends Washington. "As

we share the model with more organizations, we are inspired by the interest and creativity that are taking off to help make communities more dementia friendly."



Meeks works to partner with regional organizations to help them lead the roll out of Dementia Friends in their counties, expand awareness of the program, and be able to recruit and coordinate volunteers.

The Dementia Friends Washington team recently signed a Memorandum of Understanding with Southeast Aging and Long-Term Care, setting in motion the plan to expand Dementia Friends into eight new counties in Washington State—achieving their goal for 2023! •



Become a Dementia Friend: www.dementiafriendswa.uw.edu



#### Free technology resources and demos for the memory loss community



A core resource of the Memory Hub, the Tech Lab features 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.

"At the Tech Lab, we have had the privilege of working with on-site collaborators who share similar passion for improving the lives of people with dementia and their families, and also conducting intergenerational projects with UW graduate students to bolster cognitive and social engagement for people with dementia," says Tech Lab leader Carolyn Parsey, PhD, neuropsychologist and assistant professor of neurology at the UW School

of Medicine. "The Tech Lab continues to grow with on-site and virtual seminars, events, and our one-on-one consults, and we look forward to sharing more resources and connections with Memory Hub patrons and collaborators this year."

On the Tech Lab's docket for Spring 2023, Seattle Public Library will be joining Tech Lab for a February 21st presentation on technology resources through the library system (e.g., e-books, magazines, videos) alongside a demo of e-readers. On April 18th, the Tech Lab will hold a UW research spotlight on Technology for People with Dementia and their Care Partners, including presentations by UW Nursing and UW Social Work faculty. The event will include learning about current research projects and how to get involved in research opportunities in Technology and Aging. Registration information for these events will be available on the Memory Hub website and newsletter. Sign up for the Memory Hub newsletter: <a href="https://www.tinyurl.com/MHubNews">www.tinyurl.com/MHubNews</a> •

Visit the Tech Lab webpage to find resources, workshop materials, and more! www.thememoryhub.org/page/tech-tuesdays



#### With the Alzheimer's Café, the Frye brings music and arts engagement

Every second Tuesday afternoon, the Memory Hub fills with song and laughter. These sounds of people connecting are coming from the Alzheimer's Café, a social and arts engagement program for people living with dementia and their care partners. Participants know it as an uplifting time of spirited art discussion, live music, and garden exploration.

"In 2016 the Frye launched the Alzheimer's Café with UW Memory and Brain Wellness Center in the Frye galleries and café. Shifting the Alzheimer's Café to the Memory Hub in August 2022 has brought an opportunity to rethink it," says Mary Jane Knecht, manager of Creative Aging Programs at the Frye Art Museum. "We're excited that the new location provides wider access to the art discussion component of the program by projecting images of works from the Frye Collection and special exhibitions onto a large screeen. And the opportunity to add a stroll through Maude's Garden, or weather-permitting, singing in the garden, has brought a new delight to participants' experiences of the Alzheimer's Café."

Locating the Alzheimer's Café in the Memory Hub space blends features of both organizations. "Offering the Alzheimer's Café in-person at the Memory Hub brings depth to the experience of this program—a participant finds themselves next to great resources," says Frye Creative Aging Coordinator Samantha Sanders. "They can visit the Memory Navigator, chat with a front desk volunteer, grab resources, or explore Maude's Garden just outside."

In 2022, the talents of Frye Creative Aging staff and volunteers brought joy and energy to the Alzheimer's Café at the Memory Hub. Longtime Frye Gallery Guide Donna Dziak perfected her art of crafting the open-ended questions that guided the discussion of the renowned and intriguing artworks projected on a large screen in the Memory Hub Community Room. And the singalongs led by Frye Teaching Artist Carmen Ficarra and Memory Hub Director Marigrace Becker created a joyous and relaxed atmosphere, time after time. •

#### Photography: Jonathan Vanderweit



#### Elderwise offers spirit-centered care with art and nature

### The Elderwise Adult Day Program provides a structured program of arts, exercise, discussion and shared community for people with dementia, while providing respite for caregivers.

"It has been thrilling to offer our Elderwise Adult Day Program at the Memory Hub," says Sandy Sabersky, director of Elderwise. The Elderwise philosophy of Spirit-Centered Care is in such great alignment with the deep respect for all persons that shines at the Memory Hub. In addition, to have such a beautiful activity room to use with its direct access to Maude's Garden has been an incredible gift."

The team has heard from participants and family members that they love coming to the Elderwise Adult Day Program. "I believe it has a lot to do with being an important part of a community," says Sabersky, "and being nourished in body (exercise and food); mind (through artistic work, singing, taking in the world through the senses, discussion of important topics); and spirit (through quiet focus,



reverence, helping one another)."

Several family members of participants report that they have noticed improvements in the mood and engagement of their loved ones. One person commented that his spouse seems "puffed up" when she emerges after the day.

Elderwise's goals for 2023 include increasing diversity in the day program by working with social workers to provide two scholarship positions. They hope to offer more resources, especially a free online 'Elderwise Philosophy in Your Home' meet-up; launch their first educational module, an Overview of Spirit-Centered Care for Caregivers; and raise funds to create and market more online educational offerings. •



Learn more about the Elderwise Adult Day Program www.thememoryhub.org/page/elderwise

At left: A painting by Lynne Neville, a participant in the Elderwise Adult Day Program

#### **•** Full Life Care creates caregiver training and respite opportunities



Photo: Full Life Care

Full Life Care is a not-for-profit organization dedicated to improving the lives of people with chronic illness and disabilities and supporting caregivers. They offer a range of programs throughout the Puget Sound, from homecare to adult day health services. At the Memory Hub, Full Life Care provides a virtual caregiver education course that offers individualized coaching to help family members better support their loved ones.

The Memory Hub is also helping to create momentum around Full Life Care's effort to provide an accessible caregiver respite program, funded by the Veterans, Seniors & Human Services Levy of King County. Led by Tegenu Negi, training and outreach specialist at Full Life Care, the Caregiver Respite program provides holistic respite services through a team model approach. Negi and his team train volunteers to support low-income seniors, veterans, and their caregivers. This volunteer care team makes home visits and works with both the caregiver and the person living with dementia, in any way help is needed. This program is offered at no cost and isn't limited by functional need requirements that clients need to meet to qualify for long-term care.

The Full Life Care team reports that Caregiver Respite reached more people in 2022. They think of

a caregiver who became socially isolated as she took on fulltime caregiving duties during the pandemic. "But once we matched her with our volunteer care team, she had time to go back to her monthly social activity," says Negi. "She trusted our team and got that much needed respite."

"I'm grateful for the many relationships that we've gained in our work through the Memory Hub," says Rena Ferretti, director of Community-Based Services at Full Life Care. Ferretti feels that the Memory Hub's people and programming generate a "ripple effect" that reaches people living with dementia and their families, delivering resources and care in different and creative ways. Negi agrees, having seen how a recommendation to the Memory Hub by a Memory and Brain Wellness Center provider can lead to another



person receiving help from the Caregiver Respite team. •



Learn more about Full Life Care at the Memory Hub www.thememoryhub.org/page/dementia-training

#### Alzheimer's Association expands reach of resources

"We at the Alzheimer's Association are grateful to be part of the vibrant community space of the Memory Hub where people come for information, resources, and support, and to convene and connect," says Erica Farrell, senior clinical manager at the Alzheimer's Association, Washington State Chapter. "I'm hopeful that we can continue to raise awareness and expand our reach to more people in our communities who can benefit from our programs. It's a hard thing to hear that "I wish I knew about this support sooner" and it happens more often than folks might guess."

For the Alzheimer's Association, this first year at the Memory Hub was all about implementing a new model for people to engage with their local Washington State Chapter's staff and resources: the Memory Navigator program housed onsite at the Memory Hub.

*Em Brulotte of the Memory Navigator service* "I really like how accessible it is for people to book an in-person appointment with Em Brulotte, our Memory Navigator," says Farrell. "We've received glowing feedback from people

who have visited for one-on-one or family appointments. People have let us know they are so appreciative for the information and resources shared and have felt very supported by Em's warmth and care."

Though this partnership, both organizations are better positioned to reach the communities they serve. For example, the Alzheimer's Association and the UW Memory and Brain Wellness Center hosted the 2022 King County Community Forum: Alzheimer's Disease, Dementia, and Memory Loss. This community-focused listening session featured informational presentations and invited people to share their thoughts about how the Alzheimer's Association can help the community.

"I always think it's important to hear what people in the community identify as barriers to receive resources and support," says Em Brulotte, helpline coordinator/care consultant for the Alzheimer's Association. "When we listen to what they feel is lacking, that can give us ideas for what our group here at the Memory Hub can do that might be beneficial for others in terms of support services." •





Photography: Jonathan Vanderweit

#### Maude's Garden welcomes a second season of the Garden Discovery Program, assembles a volunteer crew

Maude's Garden, Washington State's first public memory garden, is now open to the public during Memory Hub open hours on Tues - Thurs from 9 am to 3pm. This spring, Maude's Garden team and volunteers will work to maintain and develop this beautiful place for Memory Hub visitors and program participants, who enjoy exploring and being together in Maude's Garden.

"The Memory Hub is now providing folks who love to be out in nature, along with their caregivers, with a permanent memory garden," says Peach Jack, MA, HT, Maude's Garden horticultural therapist and gardener. "A place for experiencing the changes in seasons, sparking memories, and providing a safe supportive social environment. I look forward to seeing the garden as it matures, interacting with the space in all seasons, and enjoying creative social activities with our community."

The big news is the coming addition of large ceramic pots to hold plantings that are easy to change through the seasons. This garden element is made possible by the help of Maude's Garden Volunteer Dawn Robinson, who owns Sunrise Container Garden Design.

As 2023 begins, the Memory Hub's Maude's Garden looks forward to hosting a second round of the Garden Discovery program, a collaboration between Seattle Parks and Recreation and UW MBWC. This program has long been made possible by generous support from Family Resource Home Care. "Being out in nature is naturally therapeutic," says Jack, "and with the addition of sensory programming, participants and visitors are invited to enjoy what's

Family (

Maude's Garden Project Lead, Genevieve Wanucha, communications specialist for the UW MBWC, is excited to see participants and visitors delight at the perennial plants poking up through the soil, interact with fragrant herbs and spring blooming foliage, and play with the acoustic sculpture. "It's thrilling that Maude's Garden is providing a home-base for our Garden Discovery program, she says. "This garden—complete with a gorgeous, one-of-kind stone garden bed, benches, and a sign—is becoming the enchanting gathering place we dreamed it would be. I'm just really thankful to our philanthropic donors, Richard and Maude Ferry, the Frye Art Museum, UW Medicine, Dr. Carl Westphal, and Stone Soup Gardens for making this dream come true at the Memory Hub-and for Peach Jack, Laura Rumpf, Dawn Robinson and our community members and volunteers who will help to nurture and protect this special space." •

 Image: Second system
 Visit the Maude's Garden webpage

 Image: Second system
 www.thememoryhub.org/garden

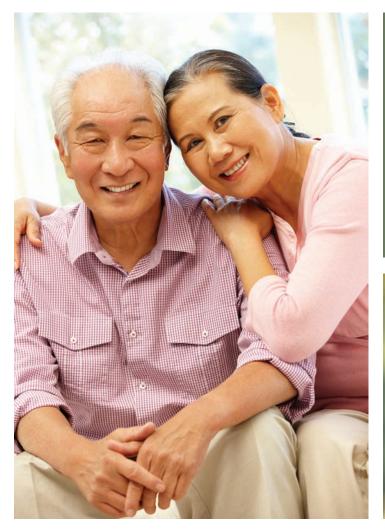
#### Thank you to all the people and organizations who donated funds to support the Memory Hub in 2022!

in bloom while engaged in both structured and independent activities. Maude's Garden is truly a healing space for all of us!"

(Current as of Jan. 1, 2023)

The Richard and Maude Ferry Foundation Charlotte H. Merritt Mr. Paul R. and Ms. Phyllis A. Seegers The Frederick Foundation M. Jean Fisher Revocable Trust Dr. Angela J. Hanson Dr. Carl Westphal California Community Foundation Mr. Richard A. Ferry and Ms. Marylou J. Ferry Deborah Van Olst Mr. Dann V. Angeloff

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UW Medicine MEMORY & BRAIN WELLNESS CENTER



# MEMORY LOSS: A GUIDE TO NEXT STEPS

A free one-time introductory class for people diagnosed with mild cognitive impairment or dementia and their families.

# 2 - 3:15 p.m. on the 2nd Thursday of the month:

## 1/12, 2/9, 3/9\*, 4/13, 5/11, 6/8\*

\*March and June sessions are **in person** at the Memory Hub, 1021 Columbia St, Seattle. Other sessions are **virtual** using Zoom (online or by phone).

Space is limited. Register at least 2 days in advance. Contact Marigrace Becker at 206-543-2440, mbecker1@uw.edu or scan QR Code to the right:





New Insights on Sleep and Dementia Risk Emerge from Unique Dataset of the Seattle Longitudinal Study



Researchers in the Iliff Lab focus on the known clinical association between dementia and poor sleep quality, such as sleeping very short or very long nightly durations.

Their latest findings emerging from an analysis of data from the Seattle Longitudinal Study, adds a new puzzle piece to their knowledge about the link between sleep and dementia risk.

Samantha Keil, PhD

The Seattle Longitudinal Study (SLS), run out of the UW Department of Psychiatry and Behavioral Sciences by Sherry Willis, PhD and the late Warner Schaie, PhD, followed the cognitive functioning of 6,000 participants from young adulthood to old age, in waves of enrollment starting in the 1956. Since 1993, the participants also completed a health behavioral questionnaire, which included a question about average nightly sleep duration, every 3-5 years.

Because of the way the SLS team collected repeated measures of sleep duration over decades, researchers can now go back to this data ask newly emerging questions about self-reported sleep and cognitive health.



Jeff Iliff, PhD

"People tend to sleep less as they grow older," says Jeff Iliff, PhD, professor of psychiatry and behavioral sciences and neurology at the UW School of Medicine. "So, our initial thought was to look at the slope of that decline in sleep with aging. For example, going from sleeping 8 or 9 hours a night in midlife, to sleeping 5 or 6 hours later in life—maybe that slope is what confers a risk of cognitive impairment."

The team did not find this association when the Iliff Lab's postdoctoral fellow Samantha Keil, PhD, analyzed data on cognition and sleep duration collected over 25 years on 1,104 adults, aged 55-100, who were participants in the SLS.

In their statistical model, Keil found that the variability, or change in sleep duration across the time measurements, showed a significant relationship with cognitive impairment.

A "variable" pattern of sleep duration, in this study, would be a participant who reported 8 hours, then 9, and then 6 hours, when assessed at the 3-5 year intervals, for example, instead of 6 hours, 6 hours, and 6 hours.

"Because SLS gives us a longitudinal dataset," says Iliff, "we were able to find that sleep variability wasn't just associated



with cognitive impairment, it actually predicted who was going to cognitively decline over that time period. So, a pattern of sleep variability is a prospective predictor, which is pretty interesting," says Iliff.

These findings shouldn't worry someone who's had a bad week or month of sleep here or there, according to Keil. "Whether or not you as an individual are a short or long sleeper in duration, if your baseline

Yeilim Cho, MD

sleep is suddenly shifting quite significantly, that's something to watch," she says.

As a next step, the Iliff Lab researchers want to know more about what factors contribute to sleep variability. A new member of the Iliff Lab, sleep physician Yeilim Cho, MD, a fellow at the VA Puget Sound Health Care System, is now working to understand the characteristics of the people who had variable sleep in this study population. Health information gathered in the SLS included factors such as diabetes and hypertension status, diet, alcohol and tobacco use, and marital and family status.

In another follow-up study, Keil will evaluate the hundreds of longitudinal MRI brain scans available from the same group of SLS participants. She is interested to know if sleep variability is associated with any known imaging markers of impaired clearance of brain waste, a potential Alzheimer's risk factor.

Iliff hopes to be able to continue learning from SLS participants, in future studies of sleep using objective measures of sleep tracking. "These are very, very committed participants," says Iliff. "They've they've put in a lot of work. They are exactly the population of people that we want to be studying moving forward."

UW ADRC Director, Thomas Grabowski, MD, professor of radiology and neurology at the UW School of Medicine, thinks that these findings and follow-up studies reveal the unique value of the SLS cohort. "It's rare to have studies where people are enrolled significantly younger than mid life, and are followed systematically over time, with neuropsychological and social developmental measures, as well as imaging measures. The SLS provides the opportunity to look at the trajectory of their cognitive development and decline over time. That makes these participants super valuable for studies of Alzheimer risk and resilience to disease." • *Genevieve Wanucha* 

Read about the Seattle Longitudinal Study, written by SLS Principal Investigator, the late K. Warner Schaie, PhD, affiliate professor of psychiatry and behavioral sciences at the UW School of Medicine. <u>www.sls.psychiatry.uw.edu/about-sls/history/</u>

#### Spotlight on Faculty Mentoring at the ADRC

The Tau Working Group: A Research Incubator



Caitlin Latimer, MD, PhD

At the UW ADRC, senior and junior investigators convene at a monthly meeting called the Tau Working Group. This mentoring and study group serves as an incubator to generate new studies and mentor junior investigators. It's a chance for investigators to bounce their hypotheses off their peers, strike up collaborations, give updates on ongoing projects, and get help with developing grant proposals that are critical to moving a career in research forward.

Caitlin Latimer, MD, PhD, assistant professor of laboratory medicine and pathology at the UW School of Medicine, who is co-leader of the UW ADRC Neuropathology Core, was still a neuropathology trainee when she joined the Tau Working Group. She now leads the discussions. "What I get out of this group is the

interdisciplinary connections and seeing how different people approach the same problem and how they think about it," she says.

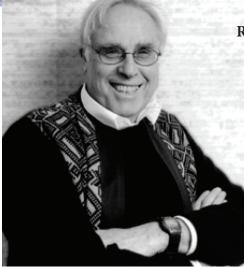
The Tau Working Group gave Latimer the chance to discuss her findings about tau and TDP-34 proteins in human brain tissue with Brian Kraemer, PhD and Nicole Liachko, PhD who study these proteins in worms genetically engineered to make Alzheimer's proteins. This interaction sparked a successful collaboration to explore her hypothesis in a basic model organism. "My K08 career award (Molecular mechanisms of synergistic TDP- 43 and tau proteotoxicity in Alzheimer's disease) really developed out of these interactions."

Nicole Liachko, PhD, research assistant professor of gerontology and geriatric medicine at the UW School of Medicine, has been involved in the Tau Working Group for several years. "It's been a great resource for collaborative ideas for my own work," she says. "My lab has contributed to two publications that resulted from discussions and collaborations formed in this group, and I expect we'll have more in the future as work in progress gets written up." Building on those papers, Liachko has received three funded grants to study aspects of protein co-pathology in Alzheimer's disease. "I'm still collaborating with other members of the Tau Working Group on those projects," she says, "so it's been incredibly fruitful scientifically."

The group owes its beginning to Thomas Bird, MD, professor emeritus of neurology at the UW School of Medicine and C. Dirk Keene, MD, PhD, professor of laboratory medicine and pathology at the UW School of Medicine. About 5 years ago, they gathered a small group to perform a detailed neuropathological study of the ADRC collection of brains from people with familial frontotemporal dementia (FTD) and mutations in the gene that codes for the tau protein (MAPT). They wanted a group with different areas of expertise on tau to focus on similarities and differences within families and between families, in order to understand how different genetic mutations affect the brain. The group has since grown in scope, turning into the interdisciplinary study group and research incubator it is today.

Kimiko Domoto-Reilly, MD, UW assistant professor of neurology, is another researcher who has benefited from developing her research project in the Tau Working Group. She is investigating an unusual imaging finding in people diagnosed with FTD during life, who donated their brains for post-mortem imaging and tissue analysis. "I have found the collaborative, interdisciplinary discussions of the Tau Working Group so informative," she says. "They guide my analysis of combining clinical assessments with neuropathologic and imaging data." The ADRC is grateful to the Takayama family for supporting this work.

"The Tau Working Group has such a good track record of converting ideas into grants and funding," says UW ADRC Director Thomas Grabowski, MD. "I see this working group as a successful model of faculty mentoring. We would like to create other such groups at the ADRC, most immediately one focused on cognitive resilience." • *Genevieve Wanucha* 



George M. Martin, MD

#### Remembering George M. Martin, MD, UW ADRC's Founding Director

The ADRC leadership is saddened by the passing of George M. Martin, MD, UW professor emeritus of laboratory medicine and pathology on December 17, 2022 at the age of 95. Here at the UW, where he has been a faculty member for 65 years, he devoted his career to studying aging and age-related diseases. He leaves a far-reaching legacy in the fields of pathology and medical genetics—areas of study in which he stayed an active and inquisitive participant at UW well into his 90s. Those with the privilege of working with him will remember his humor, collegiality, diplomacy, and generosity.

Several UW faculty members, including Drs. Peter Rabinovitch, Christine Disteche, Matt Kaeberlein, Raymond Monnat, Junko Oshima, and Daniel Promislow, remember Dr. George Martin's life and legacy in "In Memory of George M. Martin" in The Journals of Gerontology: <u>www.tinyurl.com/559dhmp5.</u>

W UNIVERSITY of WASHINGTON





Patti LaFleur and her late Mom

### The Power of Connection in Dementia Care

#### By Patti LaFleur

We all want to feel loved and connected. Being a caregiver for a loved one with dementia can be extremely isolating. Connection was one of the most important parts of my caregiving journey with my Mom—not only in being able to connect with my Mom to maintain our relationship, but also being able to connect with other caregivers to find and share resources.

Connecting with our loved one begins with treating them like the adult they are. People living with the dementia deserve dignity and respect. We often take so much away from people living with dementia, so I always thought about how I could allow my Mom to participate and make decisions in her care as much as possible. As my Mom's care partner, I always thought about what she COULD still do and not what she could not do. This looked like offering her choices, asking her to help with different tasks and building on what I knew about her as a person.

### **Creating Ways to Connect**

I connected with my Mom and supported her independence by providing her the opportunity to make choices throughout her disease progression. I allowed my Mom to make decisions in her care as much as possible. This included her choosing her clothes, activities, and meals. In the early stages, she made decisions from a wide variety of options, but as her disease progressed I limited the number of choices I offered her. She would often pick from two shirts or two art projects, but I still always allowed her to have a voice. During the late stages, I would offer her one choice and she could nod yes/no to indicate which option she preferred.

Involving my Mom in any tasks that I could and not worrying about if she did it "right" was another way I connected with my Mom and allowed her to contribute to the household. My Mom was the ultimate homemaker and she always prided herself in her ability to take care of her family and her home. So I often asked my Mom to help me with chores around the house. She would help me fold towels, which, as her dementia progressed, looked like just moving the towel around or folding the corner of the towel in. Even though she was not successfully completing the task, I always thanked her for helping, and she felt agency in her ability to help with tasks. We also baked together often. I would pre-measure and set up all of the ingredients for my Mom, she would just dump and mix. She loved being able to help with the baking (and the eating).

By building on what I knew about my Mom's likes/dislikes, I was able to help her stay connected to the activities that we did together. I used our relationship to create experiences and activities that she enjoyed. My Mom had always been a quilter, but because she was no longer able to quilt, I created art activities and crafts that allowed her to still be creative and successful in her art. We often created abstract art together because I could easily adapt it to where she was in her progression and we could focus on the process not the product. By focusing on the process, we were able to have fun and find joy together during the experience, rather than trying to create something that looked a certain way.

These activities and opportunities helped to maintain the relationship and connection that I had with my Mom. My Mom was unable to identify me as Patti or her daughter in the last two years of her dementia progression, but that did not stop her from knowing that she loved me, and that I loved her. The way that she looked at me and lit up when I walked in the room was enough proof that she able to

### **Connecting with My Community**

During my time caring for my Mom and since she has passed, I have shared our story on social media social media to connect with others, change the stigma around dementia, advocate for change, and support caregivers. Social media has become a way to honor her story by showing a different (more positive) side to dementia care. We created together, we laughed/danced and even travelled to Disneyland!

In sharing our story, I learned how important it was to connect with other caregivers. It was helpful to have other people who got what I was going through and could offer support/suggestions as I cared for my Mom. I found support groups that were targeted to my specific needs through the Alzheimer's Association and various online groups. The 24/7 helpline that the Alzheimer's Association offers can help caregivers find the resources they need. Another helpful resource for connecting with others was my local department of aging and the community resources they were able to share with me.

Dementia caregiving has so many challenges, but the connection that you can foster with your loved one and the connection you can find in a supportive community is beautiful. •

Find additional inspiration from Patti's writing for the Alzheimer's Association WA State Chapter:

www.alzwablog.org/2023/01/30/finding-joy-and-making-connections-in-dementia-care





¡HEMOS ESTADO OCUPADOS EN SU COMUNIDAD!



Hay un video que preparamos para que vea usted hoy! <u>www.memoria.uw.edu</u>

### New Spanish Language Resources for Alzheimer's19Created by the UW ADRC Outreach, Recruitment, and Engagement Core19

*The UW ADRC Community Newsletter* is available in both English and Spanish. You will find Alzheimer's education, resources, community events, and more. In the next issue, you can look forward to research updates and brain health tips. You can read or download the newsletter at <u>www.memoria.uw.edu</u> or sign up to receive this 4-page quarterly update by emailing **adrc-community@uw.edu**.

**Nuestro Boletín Para la Comunidad** Encontrará educación sobre el Alzheimer, recursos, eventos comunitarios y más. En el próximo número de la revista, puede esperar información sobre investigaciones y consejos sobre la salud del cerebro.

Lea el boletín en línea: www.memoria.uw.edu

¿Preguntas o comentarios? Correo electrónico: adrc-community@uw.edu.

### **Congratulations to the participants and supporters of SHARP!**



On November 16, 2022 at the Central Area Senior Center, SHARP participants and their supporters commemorated the successful summer pilot of the SHARP program! SHARP is a culturally celebratory neighborhood walking and reminiscing program for older Black adults.

"I enjoyed the walks because you remember what was there...and how even though it's gone, it's getting better," participant Michelle Fields. "For me, what it did was make me feel very positive again about Seattle and appreciating where I grew up."

The group got to hear from Oregon Health and Science University's Raina Croff, PhD, founder of SHARP in Portland, who helped MBWC and our collaborators launch a program adaptation in Seattle. "Standing here today is a dream come true," she said. She told the participants that the lessons learned from their experiences and feedback will make the program that much better next time-and help to bring SHARP to yet another city.

Sponsors of SHARP include Central Area Senior Center, Aging King County Seattle Human Services, Alzheimer's Association, Washington State Chapter, The Black Heritage Society of Washington State, de Tornyay Center for Healthy Aging at UW, UW Memory and Brain Wellness Center, Oregon Health & Science University (OHSU), Seattle Parks and Recreation, and Seattle Department of Neighborhoods.

#### Finding Beauty in Unlikely Places: The Art of a 20 Neuropathologist

For Desiree Marshall, MD, her imagination sparks when she looks at brain tissue under a microscope. Her art contemplates the bittersweet beauty she sees in her work as a neuropathologist.

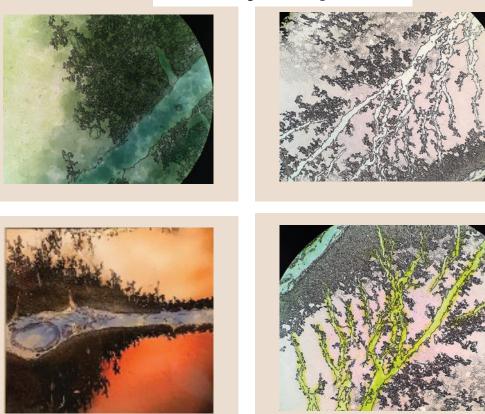
#### By Desiree Marshall, MD

I'm a very visual person, often to a fault-meaning I am easily distracted by the aesthetics of my surroundings. In large part, it was the striking beauty of tissues under the microscope, dressed in their various histologic stains that drew me to the subspecialty of pathology in medical school. To me, being a pathologist who specializes in autopsy neuropathology, has put me even more in touch with my humanity.

When it comes down to it, my clinical work is all about the decedent and their families. Despite the nourishing altruistic feelings inherent to this type of work, it can be a labor of significant emotional toll. I once felt guilty in finding beauty in diseased tissue, but no longer. Like a moth to a flame, I am drawn to the beauty of histopathology and gross anatomy—in both health and disease—a gravitational pull allowing me to do the work that others might find themselves incapable of. I have learned that something can be both beautiful and terrible at the same time; that beauty exists in many forms and can be found in the unlikeliest of places.

I found an amazing creative outlet and artistic community of like-minded brain nerds through the UW Graduate Program in Neuroscience and Eberhard Fetz Art Fund annual neuroscience themed art show, Art Neureau. I have been lucky enough to show my work at three of the exhibits and hope to participate in many more.

#### "Strange Landscapes"



Art from artifact: Glass slides for viewing under the microscope are subject to artifact, such as air bubbles under the coverslip, which can obscure the tissue beneath. These oft maligned "artifacts" can produce amazing abstract designs, inspiring the imagination. Here, artifact acts to transform these microscopic sections of the brain's cerebral cortex into *Strange Landscapes*. These images are glass slides of stained human cerebral cortex, photographed through the oculars of a microscope with iPhone 6. The photos were then digitally painted in Procreate.



Desiree A. Marshall, MD, is board certified in Anatomic Pathology, Neuropathology, and Forensic Pathology.

Dr. Marshall served as an assistant professor in the Department of Laboratory Medicine and Pathology at UW Medicine where she practiced neuropathology and autopsy pathology. She was the Medical Director of UW Medicine Autopsy & After Death Services since 2017.

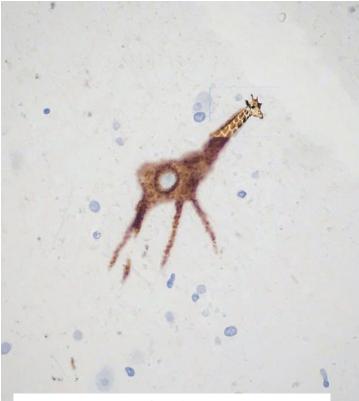
During her UW Neuropathology Fellowship research year, she worked with the UW ADRC's C. Dirk Keene, MD, PhD and Elaine Peskind, MD, and many others to secure pilot funding from the UW ADRC to found the Pacific Northwest Brain Donor Network –a research brain bank supporting studies of traumatic brain injury and the normal human brain.

In January 2023, Dr. Marshall started to practice forensic pathology full time as an Associate Medical Examiner at the Snohomish County Medical Examiner's Office, though she remains affiliated with UW Medicine and the UW Neuropathology Fellowship as an educator and collaborator.

> UW Medicine LABORATORY MEDICINE & PATHOLOGY

#### "Neuro Whimsy in 3 Parts"

As a pathologist, I find myself constantly amazed by the beauty of neurohistology, often losing myself in the pure aesthetics of these cellscapes rendered in striking technicolor. Like seeing shapes in the clouds, my mind drifts, many times envisioning the fanciful and surreal...followed by an abrupt transition to the reality of the diseases behind this bittersweet beauty.



Giraffe on the Brain

This image is based on a cortical neuron pre-tangle (an abnormal aggregate of tau protein) seen in brain tissue under a microscope. Maybe this cell was involved in a memory of a childhood carousel ride or a favorite stuffed friend.

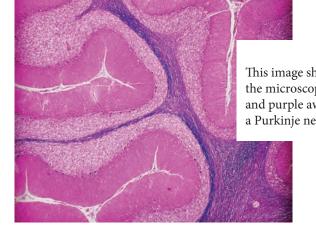


Cotton Candy

Seas of pink, fluffy amyloid plaques (Alzheimer's pathology) amidst spongy, gliottic neuropil invoked a vision of a cherished childhood treat—the sweet, simplicity contrasted by the reality of Alzheimer's disease.

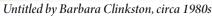


This image shows a stained section of the brain's cerebellar cortex under the microscope. On first glance, I see a saccharine vision of pure pink and purple awesomeness. On second glance, I see widespread damage to a Purkinje neuron in a person who lived with Niemann-Pick C disease.



> View more of Dr. Desiree Marshall's neuro art on Instagram at <u>www.instagram.com/pathological.beauty</u>







Untitled by Barbara Clinkston, circa 1980s

### About the Cover Artist: Barbara Clinkston (1931 - 2022)



Untitled by Barbara Clinkston, 2008

The cover art of this edition of *Dimensions* evokes the sense of community and connectedness we feel around us this year. The untitled collage is the work of our late Seattle community member Barbara Ann Clinkston (1931-2022), who was a prolific abstract painter and collage artist from the 1960s through the 1990s. She studied at the College of Art in Twickenham, England, California State University in Sacramento, and Sacramento City College in the 1980s.



Untitled by Barbara Clinkston, circa 1980s

Through later life, Barbara and her husband Bert Clinkston lived in Queen Anne, Seattle in a multigenerational-owned home with their only son David, his wife Joan Provo-Clinkston, and beloved grandson Adam from 2005 to 2022. If you were to visit Joan and David today, you would see walls full of Barbara's large artworks, some 6 feet by 6 feet.

Barbara, who lived with symptoms of vascular dementia since about 2015, passed away in October of 2022. Her husband Bert, now 100 years of age, is a World War II veteran, a former secretary of state for California, and a former political editor of the *Sacramento Union*. He currently resides at Kline Galland Home in Seattle and is visited daily by family.

Barbara's daughter-in-law, Joan was deeply involved in caregiving for Barbara, including trying to hire in-home caregivers. Joan had been very close to Barbara, whose colorful mind fascinated her and inspired her to start painting and become an artist as well. Despite the logistical challenges of family caregiving, Joan and David knew so much about Barbara that they were able to make special moments and find ways to make her happy and comfortable along the way.

Barbara, a child of England, had experienced the trauma of losing her father during the London Blitz. Amid this turmoil of 1940 and 1941, Barbara grew up knowing food insecurity. "All I needed to do was make her something freshly homemade and delicious," says Joan, "like mincemeat tarts with pie crust." One year, Joan gave Barbara a teapot as a Valentine's Day present because she always loved a strong cup of tea. "I would think about things that would give her comfort or joy or bring back memories of things that she used to love. The little things that speak to people, that speak to who they were, to bring back a little of life or spark joy-that is the goal." •

#### LEARN MORE AND CHECK YOUR ELIGIBILITY ONLINE:



### JOIN THE MOVEMENT

The Aging with Pride: NHAS Study is open now to LGBTQ+ adults turning 52-58 in 2023. We want to hear from you!

Eligible participants who complete our 30-45 minute questionnaire will be compensated with a \$20 cash gift by mail!

### AGING WITH PRIDE: NATIONAL HEALTH, AGING, AND SEXUALITY/GENDER STUDY

# Thank you to the people and organizations who donated funds to support Alzheimer's disease research or

MBWC programming in the past year!

(Current as of Jan. 1, 2023; Including donations of \$2,000 or more)

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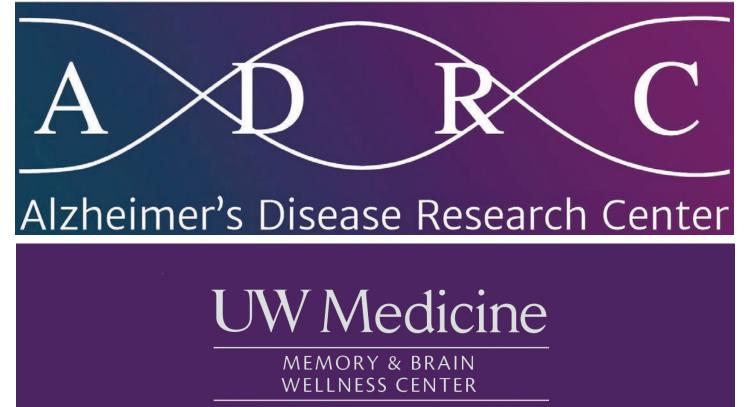
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Cover art by Barbara Ann Clinkston (1931-2022) Untitled, circa 1980s