

DIMENSIONS

The Magazine of the UW Alzheimer's Disease Research Center | UWADRC.ORG
UW Memory and Brain Wellness Center

Celebrating Our Community Champions



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- The Power of Caregiver Advocacy: A Grassroots Effort to Improve COVID-19 Vaccine Access for Vulnerable Older Adults
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- Creating a Culturally Engaging Brain Health Program for Seattle's African American Communities, One Step at a Time

Hello readers! The UW ADRC and the UW Memory and Brain Wellness Center are pleased to bring you *Dimensions* for Spring and Summer 2021!

Amid the challenges our whole world has faced this past year, we have been impressed and inspired by efforts of our community members to make a difference in the world of dementia care and research and advocate for people living dementia and their families. Our new issue focuses on their efforts. Here are some highlights:

- Caregiver Laure Brooks has worked to help her partner Joe Liao to offer tai chi classes through a window of a memory care facility in Bellingham, WA.
- Caregiver Trang Tu is engaged in a grassroots community advocacy effort to ensure access to the COVID-19 vaccine for elders being cared for at home and family caregivers within immigrant and refugee communities.
- Karen Winston, Seattle's City Liaison for the Mayor's Council on African American Elders, is partnering with the MBWC to launch an innovative brain health program for African American communities next year, an adaptation of the SHARP program led by Oregon Health & Science University's Dr. Raina Croff.
- Kevin Kvarda, back once again as a *Dimensions* contributor, shares the next chapter of his creative advocacy project to help people navigate the experience of being diagnosed with memory loss.
- Maureen Cardosa, San Diego resident, has launched a UW Medicine Accelerate Medicine campaign to run the Dublin Marathon and raise donations for the UW Alzheimer's disease research fund.

We hope these stories bring you a sense of community! In this issue, you will also learn about findings from new studies that relied on the data and specimens donated by research participants enrolled in the ADRC's Clinical Core and in the Adult Changes in Thought Study. We highlight newly funded projects in Alzheimer's research, including a study to improve support groups for Lewy Body Dementia caregivers. The latest installment of our Indigenous Aging Brain Health Series features a conversation with Dr. Gary Ferguson (Aleut/Unangax) about traditional foods, ways of healing, and Indigenous elder wisdom. As always, we continue our work to advance understanding of Alzheimer's disease and related disorders, on a foundation of community trust and support. We hope you take away an encouraging message about Alzheimer's disease and related conditions: people living with memory loss and dementia have much to offer, strengths to work from, and wisdom to share.

We continue to be grateful for your interest in and support of our work. The Ellison Foundation, the Richard M. and Maude Ferry Charitable Foundation, the Paul V. Martinis Estate, the Anderson Foundation, the Sky Valley Whirlwinds, Frye Museum, AARP, City of Seattle Parks and Recreation, Alzheimer's Society of Washington, Washington Association of Area Agencies on Aging, University of British Columbia, SW Washington Agency on Aging and Disabilities, Emerald Heights Retirement Community, Richard M. Ferry, Ms. Charlotte Merritt, Aaron J. Colwell, Debby Hanssen, Cheryl Guenther, and other generous individuals and groups make it possible for us to move faster in research and reach further into the community than ever before. Your interest also 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!



Thomas Grabowski, MD
UW ADRC Director



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



Genevieve Wanucha, MS
Dimensions Editor

UW ADRC Leadership

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Associate Directors C. Dirk Keene, MD, PhD, Suman Jayadev, MD, Eric Larson, MD, MPH, MACP

Emeritus Director George M. Martin, MD

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ORE Core Leader Kimiko Domoto-Reilly, MD

Satellite Core Leader Dedra Buchwald, MD

Data Management and Statistics Core Leader Ellen Wijsman, PhD

Precision Neuropathology Core Leader C. Dirk Keene, MD, PhD, **Co-Leader** Caitlin Latimer, MD, PhD

Research and Education Component Leaders Jeffrey Iliff, PhD, Brian Kraemer, PhD

Communications Genevieve Wanucha, MS

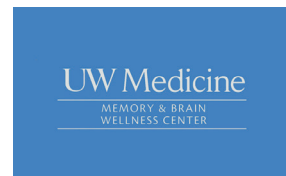


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DIMENSIONS The University of Washington Alzheimer's Disease Research Center (UW ADRC) is affiliated with the UW Medicine Memory and Brain Wellness Center (MBWC) and the Veterans Affairs Puget Sound Health Care System (VA). The UW ADRC has been funded 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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DISCOVERIES MADE POSSIBLE BY YOU

These studies used data from research participants in the UW ADRC or the Adult Changes in Thought Study and were made possible in part by funding from the National Institute on Aging. Find more highlighted studies on our Discoveries Made Possible by You page on uwadrc.org!

Medications and Dementia Risk

Glucose-Dementia Association Is Consistent Over Blood Pressure/Antihypertensive Groups. Zhou J et al. March 2021. Shelly Gray, Zachary Marcum, Douglas Barthold, Wayne McCormick, Susan McCurry, Eric B. Larson, Paul Crane

High glucose levels in the body are associated with dementia risk in people with and without diabetes. However, little is known about how this association might be affected by high blood pressure (antihypertensive) treatments. Most studies on modifiable dementia risk factors so far have considered each factor in isolation. These researchers wanted to test the hypothesis that hypertension and antihypertensive treatments may modify these links between glucose levels and dementia. They analyzed data generated from the Adult Changes in Thought Study, a population-based longitudinal cohort study of community-dwelling older adults in Seattle, who are enrolled at age 65 and followed to autopsy. These data included glucose measures, diabetes and antihypertensive treatments, and blood pressure data on 3,056 participants, with a mean age of 75.1 years, without diabetes treatment and 480 with diabetes.

The researchers found that higher glucose levels were associated with greater dementia risk among people, both with and without treated diabetes, in line with previous work. However, hypertension and antihypertensive treatments did not appear to affect the association between glucose and dementia risk in the ACT Study. This finding suggests that taking high blood pressure medications may not make a difference in the dementia risk linked to high glucose levels, for older adults. Future studies are still needed to examine this question among midlife adults and to see if there is any variation in results when different types of antihypertensive treatments are tested individually.

If untreated, hypertension is also a cardiovascular contributor to dementia. When hypertension can't be managed with exercise, stress reduction, and diet, several antihypertensive medicines are available. Another 2021 ACT study suggests that some medicines might be better than others at reducing dementia risk. The findings support that angiotensin II-stimulating medicines are potentially better than angiotensin II-inhibiting medicines for reducing dementia risk.

Genetics and African American Ancestry

Novel Alzheimer Disease Risk Loci and Pathways in African American Individuals Using the African Genome Resources Panel: A Meta-analysis. Kunkle BW, et al. January 2021 / Eric B. Larson, Paul Crane, Thomas J. Grabowski, Walter Kukull, Thomas Bird, C. Dirk Keene, Shubhabrata Mukherjee, Elaine Peskind, Gail Jarvik, Wayne McCormick, Susan McCurry, Murray Raskind, Debby Tsuang, Chang-En Yu

In this study, the researchers analyzed genetic data from the Alzheimer Disease Genetics Consortium to compare the DNA sequences from more than 8,000 African Americans, with and without Alzheimer's disease. The UW ADRC, along with multiple ADRCs, contributes genetic data to this project. The researchers found that the main biological pathways linked to Alzheimer's risk in African Americans largely overlapped with those in non-Hispanic white individuals, but several disease-associated genetic loci in these pathways differed. A genetic locus (plural: loci) is the specific, fixed position on a chromosome where a particular gene is located. This finding suggests that these pathways, including those responsible for immune response, intracellular transport, nervous system development, and fat metabolism, are not ethnicity-specific and are important in understanding Alzheimer's disease risk across ethnic groups. But, differences in the genetic loci in these pathways could prove to be additional targets for further investigation into ethnic difference in risk.

The researchers also found a link between kidney system development and Alzheimer's risk in African Americans, suggesting another novel disease mechanism to explore. African Americans are three times more likely to experience kidney failure than non-Hispanic whites. They are also more likely to have both dementia and kidney disease. Further research to understand this connection will be important for the prevention and treatment of Alzheimer's disease for African Americans.

This study provides new insights about the biological pathways and genetic factors that contribute to the development of Alzheimer's in African Americans, and more importantly shows how the genetic loci can differ significantly between ethnic groups. Understanding these differences is essential to develop effective treatments for African Americans and to understand the biology underlying observed health disparities.

* Only UW/ACT researchers are listed

Therapeutic Targets

The association of circulating amylin with β -amyloid in familial Alzheimer's disease. Ly H et al. January 2021 / Angela Hanson

Current therapeutic strategies to treat or prevent dementia are aimed at trying to interrupt the accumulation of amyloid beta protein, a hallmark pathology of Alzheimer's disease. Another growing approach in the field aims to intervene earlier in the process. One example involves targeting levels of certain proteins circulating in the blood that can interact, or 'cross-seed,' with amyloid beta protein and initiate a disease process. Specifically, cross-seeding is a biological event in which a protein can trigger the aggregation of different species of amyloid beta, forming toxic amyloid. Recent data from multiple research teams suggest that one of these potential modifiers of Alzheimer's pathology is amylin protein, which is a metabolic hormone produced in the pancreas and circulates in the blood.

This study out of the University of Kentucky assessed whether circulating human amylin cross-seeds with amyloid beta early in the course of Alzheimer's disease. The researchers used brain and spinal fluid samples from individuals affected by familial Alzheimer's disease, and unaffected controls from the UW ADRC and other centers. In their analysis, the team found evidence for cross-seeding between amylin and amyloid beta in the brains of participants affected by familial Alzheimer's disease. They also found, in a rat model of human Alzheimer's, that suppressing amylin protected against Alzheimer's-associated effects, while intravenous injection of human amylin worsened Alzheimer's pathology.

These results demonstrate a role of circulating amylin in early Alzheimer's disease and suggest that restoring the proper physiological balance of amylin may reduce Alzheimer's pathology. The researchers suggest that development of anti-amylin drugs may improve the lives of familial Alzheimer's disease mutation carriers and slow the progression of sporadic Alzheimer's disease.

Air Pollution and Alzheimer's Neuropathology

Fine Particulate Matter and Markers of Alzheimer's Disease Neuropathology at Autopsy in a Community-Based Cohort. Shaffer R et al. February 2021/ Rachel M. Shaffer, Ge Li, C. Dirk Keene, Caitlin S. Latimer, Paul K. Crane, Eric B. Larson, Joel D. Kaufman, Marco Carone, Lianne Sheppard

Air pollution contains solids or liquid droplets so small that they can be inhaled and cause bodily damage. Particles less than 2.5 micrometers in diameter, also known as fine particulate matter (PM_{2.5}), pose risks to health, including brain health. Growing evidence links fine particulate matter exposure to Alzheimer's disease, possibly through oxidative stress and inflammation. Researchers at the ADRC and Adult Changes in Thought Study (ACT) have published the first evaluation of the association between long term exposure to fine particulate matter and Alzheimer's disease neuropathologies, using older adult brain autopsy samples.

The researchers leveraged extensive air pollution exposure data to examine their research question. They used a newly developed air pollution exposure prediction model, specifically developed from Puget Sound air monitoring data and study-collected low-cost sensor measurements. This model provided estimates of fine particulate matter exposures at the study participant home residences from 1978 to 2018. They found that 94% of the individuals had experienced 10-year exposures below the EPA national ambient air quality standard, meaning they had relatively low exposure concentrations of fine particulate air pollution. These individuals also mostly self-identified as white and middle class, with relatively low rates of co-occurring health problems.

Researchers analyzed autopsy specimens from 832 deceased participants enrolled in the ACT study. They found a suggestive increase in the odds of having more serious Alzheimer's pathology, as defined by neuritic plaques, in those participants with relatively higher exposures to fine particulate matter. However, when the researchers looked at other neuropathological markers relevant to Alzheimer's, such as tau tangles, results were conflicting, rendering the overall study findings inconclusive.

The researchers suggest that because of the low variation of air pollution levels at the residences, the study may not have had enough statistical power to estimate adverse neurological effects of the low exposures experienced by the cohort. They also suggest that the known risk of Alzheimer's disease linked to fine particulate matter may be related to mechanisms other than the formation of tau tangles and amyloid plaques. Finally, more advanced statistical methods are needed to untangle these autopsy findings from the well-understood premature death associated with particulate matter exposure. Going forward, ADRC and ACT researchers aim to enroll and follow individuals from more diverse populations with different risk factor profiles to see whether or not these results can be generalized more broadly. •

NEW GRANTS AND FUNDING

Researchers in the UW Alzheimer's community recently received the following career awards and funding for exciting new projects.

Division of Gerontology & Geriatric Medicine

Effects of apoE Isoform, Sex and Diet on Insulin Regulation in Brain: Investigating the impact of apoE, sex, and age on SARS-CoV-2 blood brain barrier transport and cognitive effects. NIH RO1, **Elizabeth Rhea, William Banks**

Effect of Central FGF1 Treatment on Perineuronal Net Assembly in Alzheimer's disease. NIH/NIDDK, NOT-DK, **Michael W. Schwartz, Kimberly Alonge**

Identifying an Ophthalmic Combinatorial Biomarker of Early Alzheimer's Disease Using Novel Imaging and Deep Learning. Alzheimer's Drug Discovery Foundation grant, **Cecilia S. Lee**

Department of Neurology

"The Brain and Maternal Microchimerism: Characterizing transcriptomal status and phenotype of microchimerism-derived cells in the human brain within the context of refractory epilepsy. NIH/NINDS R21, **J. Lee Nelson, Jonathan Weinstein.**

Multidisciplinary Clinical Research Career Development Award. UW ITHS KL2, **Jonathan Weinstein**

White Matter Injury and Protection: Mechanisms, Outcomes, and Translational Assessments - Developing methods of assessing white matter integrity and protection in the rodent brain with an emphasis on electrophysiological and magnetic resonance imaging modalities. NIH/NCATS KL2, **Ashley McDonough, Jonathan Weinstein (Mentor)**

Single Cell RNA sequencing Transcriptomic Analysis of Ischemic Preconditioned Microglia. NIH/NINDS, R03, **Jonathan Weinstein**

Department of Physiology and Biophysics

The Relationship between Inflammation and Cognition in a Monkey Model of Human Aging. NIH Supplement to the Primate Center P51 grant, **Beth Buffalo**

Department of Psychiatry and Behavioral Sciences

Validating a Non-Invasive Method to Measure Water Transport in Brain Health and Disease. UW Medicine Garvey Institute for Brain Health Solutions, Innovation Grant, **Jeffrey Iliff, Deidre Jansson**

Department of Laboratory Medicine & Pathology

Cortical Somatostatin Interneuron Dysfunction after Trauma: Role in Cognitive Flexibility. NIH K08 (Career Award Transfer from UCSF), **Amber Nolan**

Neuroinflammation and Neural Circuit Dysfunction in Traumatic Brain Injury. Martin-Reichenbach Fellowship Award, **Amber Nolan**

True-Brown Fellowship Award. UW Department of Laboratory Medicine & Pathology, **Amber Nolan**

High Resolution Profiling of Senescent Neurons and Their Microenvironments in Postmortem Human Brain Tissue Spanning Eight Decades of Life. NIH R01, **C. Dirk Keene**

Oligodendrocyte Progenitors and Hyaluronan-mediated Mechanisms of Human Vascular White Matter. NIH RFA, **C. Dirk Keene**

Transforming Research and Clinical Knowledge in Traumatic Brain Injury (TRACK-TBI): Identifying the causes, risk factors, biomarkers and prognoses for patients with traumatic brain injury. National Football League, **C. Dirk Keene**

School of Nursing

Mediterranean Diet App for Individuals with Frailty and/or Dementia, as well as Their Care Partners. de Tornay Center RIFP, **Oleg Zaslavsky**

Department of Radiology

Synthesizing Positron Emission Tomography (PET) Data from MRI using Deep Learning. UW Medicine Garvey Institute for Brain Health Solutions, Innovation Grant, **Hesamoddin Jahanian, Thomas Grabowski**

The Adult Changes in Thought Study

Pregnancy Complications and the Development of Alzheimer's Disease and Related Dementias in Women in the Adult Changes in Thought study. NIA R21, **Eliza C. Miller (Columbia University)**



Dublin for Dementia: Maureen Cardosa's Marathon Effort to Support UW Alzheimer's Research

For San Diego educator Maureen Cardosa, running is more than a way to stay healthy. She runs to raise funds for Alzheimer's disease research in honor of her mother, Rosemary "Rosie" Gaither, who has lived with this disease for two decades. "My passion for running is a way for me to put my energy into something positive that can make a difference and connect people," she says. Now, at "58 years young," Maureen is training for her 7th long-distance race: the [Dublin Marathon](#) on October 24, 2021. This fitness effort is part of a [UW Medicine campaign](#) to gain donors for the UW Alzheimer's Disease Research Fund.

"Everybody loves Rosie," says Maureen. "She is just such a kind person, and she was always the life of the party. It's been really hard to see her affected by dementia. I think there's so much more going on inside than she can express in words. When she hears my sister and I talk and tell stories, you can see her eyes light up and she'll laugh, so we know she's still in there."

Maureen is the Husky Mom of Jake Wambaugh, a scholarship athlete from UW Coach Chris Petersen's first recruiting class (2014). Through this natural connection to the UW, she learned about the opportunity to launch a UW Medicine Accelerate Medicine campaign to support Alzheimer's disease research. UW videographer Payton Wagner offered to help her create a professionally produced [video](#) to spread awareness of the campaign.

In addition to sharing the promotional video, Maureen posts daily workout routines, exercise and healthy eating tips, and inspirational updates about her training progress to [Instagram](#) to promote the campaign. "I really want to inspire others to look at life differently and get out there and take care of themselves, physically through their own passion. I am trying to give them pieces along my journey," she says. Her followers and campaign supporters cheer her on and push her to continue.

But she couldn't have done it without her son Jake, who helped her plan the fitness component of her campaign. For Christmas, Jake wrote his mother a complete workout plan, based on his research about marathon running and his many years of weight training experience. "He's amazing," says Maureen. When she started to become worried about the impact of the COVID-19 pandemic on her plans, he told her, "Mom, what are you worried about? You're going to raise the funds, no matter what."

While researching the work of the UW Alzheimer's Disease Research Center, Maureen [read about George Martin, MD, Professor Emeritus of UW Pathology](#), who founded the UW ADRC in 1985 and contributed insights into the fundamental biological mechanisms of aging, brain health, and Alzheimer's disease. She resonated with his big-picture perspective on the importance of early childhood education for the development of future healthy brains and critical thinking skills. This subject happens to be Maureen's other passion, which motivates her work as Director of Preschool and Junior Kindergarten at the Warren-Walker School in Point Loma. After getting the chance to speak with Dr. Martin, she is even more excited to partner with the UW ADRC. "It's all come full circle for me," she says •

> View Maureen Cardosa's campaign film: <https://youtu.be/HaS3bmQKtlc>

> Become a sponsor at www.acceleratedmed.org/maureen-cardosa

Flip to Page 8 to read all about the 2021-2022 ADRC Development Projects that encourage investigators to use ADRC resources to advance the understanding, diagnosis, or treatment of Alzheimer's disease.

ADRC Awards for New Ideas in Alzheimer's Research: 2021-2022

Learn about the newly funded 2021-2022 ADRC Development Projects. These awards encourage investigators to use ADRC resources to advance the understanding, diagnosis, or treatment of Alzheimer's disease.



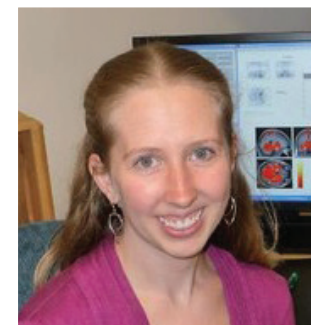
Brain glycan sulfation recoding in Alzheimer's disease

KIMBERLY ALONGE, PHD. ACTING INSTRUCTOR, UW MEDICINE

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. Recent research, including Dr. Alonge's previous work, shows that Alzheimer's disease leads to losses of important structures within this matrix, called 'perineuronal nets', that normally help to maintain the integrity of brain circuits involved in memory and cognition.

In this new ADRC-funded project, Dr. Kimberly Alonge will leverage ADRC resources to identify neuropathological mechanisms behind changes in the extracellular matrix in both postmortem human brain tissue and in pre-clinical rodent models of Alzheimer's disease.

Dr. Alonge will extend her previous work with mass spectrometry technology to quantify biological changes in brain tissue. She will rely on the UW School of Pharmacy's Mass Spectrometry Center to analyze samples from the carefully curated human brain tissue resources of the UW ADRC Precision Neuropathology Core. She will also continue her ongoing work with ADRC's Brian Kraemer, PhD, to determine whether loss of perineuronal nets in a rodent model of Alzheimer's disease associates with disease progression. Through these resources, this award will help Dr. Alonge advance our knowledge of neurodegenerative disease pathophysiology.



Understanding microglia responses in resilience, cognitive decline, and neuropathological proteopathy

KATHERINE PRATER, PHD. POSTDOCTORAL RESEARCH FELLOW (JAYADEV LAB), DEPARTMENT OF NEUROLOGY, UW MEDICINE

Microglia, the immune cells of the brain, normally orchestrate protective inflammatory responses. On the flipside, evidence shows that neuroinflammation is a key driver of Alzheimer's disease pathology. In the Jayadev Lab, Dr. Katherine Prater studies how the brain's immune sentinels respond to the presence of Alzheimer's disease pathology, particularly in individuals who were resilient to Alzheimer's disease during life. "Resilience" refers to the subset of individuals who live until late life without developing symptoms of dementia, yet show relatively high levels of Alzheimer's disease neuropathology in their brains at post-mortem autopsy. These individuals seem to have overcome the

presence of pathological proteins such as amyloid beta and tau and remain cognitively normal despite pathology—and may hold clues to the biological mechanisms of resilience.

In this new ADRC project, Dr. Prater will investigate the gene expression and immune activation profiles of microglia from autopsy specimens from resilient individuals and from those who had dementia during life. This study aims to reveal how neuroinflammation differs between individuals who do and do not show resilience to Alzheimer's disease, providing a starting point from which to assess the potential for new pharmacological targets.

ADRC resources play a key role in this development project, which leverages human tissue samples from the ADRC Precision Neuropathology Core, matching clinical data from the ADRC Clinical Core, and expertise from the ADRC Data Management and Statistics Core.



Plasma phosphorylated tau protein and Alzheimer's disease in American Indians: The Strong Heart Study

ASTRID SUCHY-DACEY, PHD. ASSISTANT PROFESSOR, ELSON S. FLOYD COLLEGE OF MEDICINE, WASHINGTON STATE UNIVERSITY

Dr. Astrid Suchy-Dacey is interested in furthering innovative research that focuses on detecting and accurately diagnosing Alzheimer's disease and related dementias in American Indian communities. Because rural American Indian reservations have limited access to specialty neurology care centers, these communities would greatly benefit from non-invasive, low-cost, efficient diagnostic tools that use relatively basic laboratory technologies. One newly available option in this regard is a blood test for tau, a hallmark protein pathology of Alzheimer's disease.

Recent research shows that measures of a certain form of abnormal tau protein (p-tau181) can serve as a potential blood plasma biomarker test for Alzheimer's disease and other dementia pathologies. P-tau181 correlates closely with multiple markers of disease severity and symptom profile, and it can distinguish patients from healthy controls with high precision. This ADRC-funded pilot project will conduct the first measures of p-tau181 in American Indian elders using stored blood plasma samples from the Strong Heart Study. This study conducted MRI brain scans, cognitive testing, clinical evaluation, and collected blood plasma in a cohort of American Indian elders in Oklahoma, South Dakota, and Arizona over the last decade.

Dr. Suchy-Dacey will determine the extent to which p-tau181 plasma assays distinguish Alzheimer's dementia from normal cognitive aging in American Indians. She will also examine associations of p-tau181 plasma assays with previously-collected MRI volumetric brain imaging measures. This pilot study will explore the feasibility of using these tau assays for biomarker measurement in larger studies in this unique population.

Along with the valuable data from the Strong Heart Study, this project leverages ADRC resources in the form of mentor expertise as well as the use of existing ADRC data.



Using metabolic network modeling to improve the maturity of iPSC-derived microglia for Alzheimer's disease

YULIANG WANG, PHD. RESEARCH ASSISTANT PROFESSOR, PAUL ALLEN SCHOOL OF COMPUTER SCIENCE AND ENGINEERING/INSTITUTE FOR STEM CELL & REGENERATIVE MEDICINE, UNIVERSITY OF WASHINGTON

Researchers in the UW ADRC Neuropathology Stem Cell component can generate living microglia from patient-derived induced pluripotent stem cells. These cells hold great promise for modeling Alzheimer's disease and testing the effect of potential therapeutics. Computer scientist Dr. Yuliang Wang aims to tackle a major roadblock in stem cell research, which is that derived microglia act like fetal immature microglia, which may pose significant challenges for modeling Alzheimer's disease, an

adult-onset disease that develops with age.

In this ADRC-funded project, Dr. Wang will develop and validate a computational method to identify metabolic interventions that will enhance the maturity and function of stem cell derived microglia, in order to accurately model neuroinflammation in Alzheimer's disease in a dish. This project is a close collaboration with the UW ADRC's Suman Jayadev, MD, and Jessica Young, PhD. The team will generate microglia from patient-derived stem cell lines and measure the characteristics of the cells before and after testing the metabolic interventions predicted to be most promising by the new computational model.

This project will introduce new ways to identify metabolites and enzymes important for microglia maturation, validating their function in vitro systems, and producing more mature and functional derived microglia for modeling neuroinflammation in Alzheimer's disease.

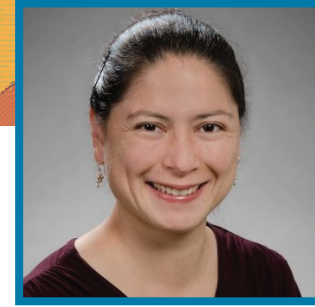
Adapting Online Support Interventions for Lewy Body Dementia Caregivers



Oleg Zaslavsky, PhD



Annie Chen, PhD



Kimiko Domoto Reilly, MD

Oleg Zaslavsky, PhD, an associate professor in the UW School of Nursing, focuses on developing technological interventions to promote the health and resilience of older adults. Virtual resources, such as mobile apps and online discussion platforms, can keep families informed and connected—and never more so than during the stay-at-home order. When the pandemic hit, Zaslavsky and his team found themselves in a unique position to explore the value of their online support program for different vulnerable populations.

Since 2015, Zaslavsky and his team have created and evaluated Virtual Online Communities for Aging Life Experience (VOCALE), an online platform for older adults living with frailty to discover new management strategies and discuss their symptoms, such as pain, weakness, tiredness, low mobility, and sleep difficulties. In several pilot studies that ranged from 8-10 weeks, participants reported positive changes in their lives and health. They came away better able to leverage their own knowledge to improve their strategies to deal with daily medical challenges.

After receiving needed training and instruction, VOCALE participants log in at regular intervals, engage in educational didactics, and interact with each other through written messages. They share about their own experience, but they also share their strategies. For example, one person talked about taking boxing lessons to improve her balance. Another person talked about a creative solution to improve her sleep.

Fundamentally, VOCALE aims to promote 'resilience', a term in psychology for the capacity to bounce back after stress and adapt to challenges. Zaslavsky's approach focuses on a major pillar of resilience called 'self-efficacy,' or the extent to which people believe that they can help themselves. The VOCALE team aims to tap into a person's inner resources and encourage a sense of control over their situation.

"We learned that the core elements are enhancing person-to-person connection and helping them to think about their problem-solving skills," says Zaslavsky. Through exchanging ideas and learning from each other, participants gained the confidence and empowerment that comes with improved self-efficacy.

Now, in a new collaboration with UW Medicine and UW Memory and Brain Wellness Center, a multi-disciplinary team will customize this online platform for people who have unique life

experiences and urgent unmet needs: caregivers of loved ones with Lewy body dementia. VOCALE-LBD will enable participants to share their experiences in a supportive space and build problem solving skills to help them in their caregiving and their efforts to stay healthy.

The effort is one of eleven big ideas selected for an Innovation Grant award by the UW Medicine Garvey Institute for Brain Health Solutions. Along with Zaslavsky, the leaders of this project include Annie Chen, PhD, of the UW Department of Biomedical Informatics and Medical Education and Kimiko Domoto-Reilly, MD, a neurologist at the UW Memory and Brain Wellness Center and PI of the UW Lewy Body Dementia Research Association Center of Excellence. She will bring clinical expertise in the experience of this type of dementia to this team.

The Lewy body dementias (LBD), 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 LBD report higher stress and more severe depressive symptoms.

"Providing effective support infrastructure for caregivers of people with Lewy body dementia remains challenging, especially in the setting of the pandemic," says Domoto-Reilly. "Moreover, support groups for caregivers of people with other dementia-related conditions might not address critical issues specific to LBD. We hope an intervention like VOCALE-LBD can begin to open doors to better support and care."

First, the team wants to learn from caregivers themselves. The team is now conducting virtual individual interviews and focus groups to help them understand caregivers' experiences, needs, and priorities. Then they will develop and test the re-designed intervention in a pilot study focused on usability and effectiveness in improving health outcomes.

By engaging in human-centered, community-driven design of this online support system, this Garvey Innovation project will begin to lay the groundwork for promoting resilience within families affected by the behavioral challenges of dementia in our increasingly virtual world. •

If you want to learn more about this study, please contact the study team at vocale@uw.edu or 206-880-0410.



Twitter As a Career Development Tool for Researchers

Inspired by the 2021 RCCN & Partners Webinar: Social Media as a Tool for Career Development by Research Centers Collaborative Network, NIA, NIH/AGING Initiative/ RCMAR Coord. Center, OAIC Early Career Faculty Group, US Deprescribing Network, Nathan Shock Centers Coordinating Center, and Clin-STAR Coordinating Center.

► Strategically using social media can expand and track the reach of your work and build your national profile.

Why use Twitter as a Researcher? You can...

- Disseminate the message of your peer-reviewed publications or projects to news outlets, the public, and colleagues!
- Promote discussions and engagement around new research findings from your field.
- Get more talk invitations and attract the attention of journalists and science writers at your university.
- Reach specific subgroups of people who are interested in your specialty.
- Advocate for the causes in research and medicine that you care about.
- Make connections with other researchers and instantly interact with leaders of NIH/NIA, government, and university departments.

*Be sure to read "Your Quick and Easy Guide to Our Social Media Guidelines" from UW Medicine. While your personal social media profiles are your own, as a UW Medicine employee, there are social media guidelines and policies to keep you out of posting predicaments. "You know what they say: The Internet is forever." Link: <https://huddle.uwmedicine.org/your-quick-and-easy-guide-to-our-social-media-guidelines/>

Tips to Make the Most of Twitter:

- Altmetrics scores articles based on their reach and popularity on social media and traditional media. Visit <https://www.altmetric.com/audience/researchers/> to learn more. These free tools can be used for professional development, ensure your work is being seen by right audiences, and improve the strategy for targeting your posts.
- Add images to your posts. Use publicly available images from your papers to illustrate your post. Use Canva.com to create graphics for social media.
- Take advantage of the "List" feature on Twitter to curate lists of accounts representing a specific interest, i.e., 'microbiome researchers'. This allows you to display real-time posts of specific accounts without needing to actually "follow" the accounts. Subscribe to public lists made by other researchers you know.
- Add links to your professional social media accounts in your email signature and website. Coordinate with your department, which likely has an account and can support you.
- Follow hashtags of big events and conferences, such as #ADSummit2021 #AAIC2021 #AAICNeuroNext

• **Don't have the time or desire to cultivate a social media presence as a researcher? No problem! Take advantage of MemoryBrain_UW Twitter! Let us cover your work and/or spread the word on social media! Get in touch by emailing gwanucha@uw.edu.**

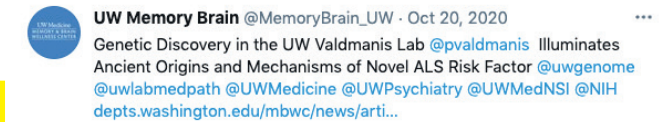
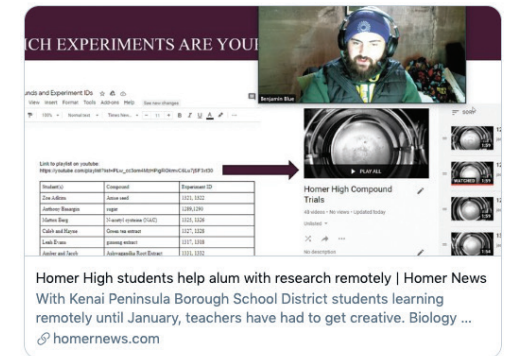
• Tag [@MemoryBrain_UW](https://twitter.com/MemoryBrain_UW) in your own posts, if relevant.

Examples of Twitter accounts for UW Alzheimer's researchers to follow:

Institutional accounts: @MemoryBrain_UW, @UWMedicine, @uwmnewsroom, @uwnews, @UWDeptMedicine, @halo_uw, @UWMedNSI, @KPWaResearch, @UWRadiology, @uwlabmedpath, @AllenInstitute, and many more!

National organizations/efforts: @Alzheimers_NIH, @ALZ_WA, @ISTAART, @ClinSTARCC, @RCMARCC

Scientific resources and news: @AMiNDR_podcast, @alzforum, @AMPADPortal, @Model_ad_alz, @fdtalk, @allFTD





The Power of Caregiver Advocacy: A Grassroots Effort to Improve COVID-19 Vaccine Access For Vulnerable Older Adults

By Genevieve Wanucha

Among 840,000 unpaid family caregivers in Washington State, there are 353,000 who care for a loved one with Alzheimer's or another dementia. Among them is Trang Tu, a Vietnamese refugee who immigrated to the U.S. in the 1970s. She is a community organizer and devoted caregiver for her 90-year-old mother, Anna Nguyet Dang. During the pandemic, the restrictions prevented Tu's out-of-state siblings from visiting to help care for their mother. Without extra help, Tu left her job as a consultant to care for her mother full time and prevent falls or injuries that would require going to the hospital.

"I felt like the only way to protect her was going to be a vaccine," Tu said. She followed along with news on the vaccine development, and especially the plans for vaccine eligibility and distribution. Early in December 2020, the Centers for Disease Control (CDC) issued guidance for states that the first group to receive the vaccine should be long-term care residents and health care workers. There was no mention of elders being cared for at home. Tu searched to find out whether people like her mother would be in the next priority group. All she could find were graphics of vaccine eligibility phases showing adults over 65 not in long-term care.

"Families like ours are going to fall through the cracks," Tu said. "And, that

is when the light bulb went off, and I became alarmed. I was reminded that taking care of our elders at home is more common for a lot of families of color, and refugee and immigrant communities, in particular, based in cultural values or out of financial necessity and lack of culturally appropriate care facilities."

According to the National Asian Pacific Center on Aging, 42% of Asian American and Pacific Islanders are caregivers, compared with 22% of the general population.

Tu remembers the days leading up to Christmas as a whirlwind of work to advocate on behalf of home caregivers and their loved ones. Having learned last minute that the CDC was holding a virtual Advisory Committee on Immunization Practices meeting on December 20, 2020, Tu quickly wrote up talking points for herself and four of her family members. They had secured limited slots to speak in the one-hour public comment period. During their time, they asked that dependent elders in home care be prioritized in the CDC's advice to states on vaccine allocation. With their voices heard by national officials and journalists, Tu turned her attention back home, to Washington State.

Reaching out to an initial group of community leaders and advocates, they drafted a letter to the Governor

and the State Secretary of Health to call out the invisibility of vulnerable communities in the state's draft vaccine plan. They highlighted the inequitable access for vulnerable elders, many of whom don't have the technology, know-how, or language to search for vaccine appointments or register for one. They had only a few days to circulate the letter, but they garnered the support of 87 organizations and 130 individuals who co-signed the petition. This group would continue on and grow as an informal community coalition advocating for vaccine equity in the months to come.

"I wasn't trying to compete with other groups, but I wanted to make sure that elders being cared for at home are visible," said Tu. "The home is not the same group setting of a long-term care facility, but there may be just as significant of a risk when you have multi-generational households with people who are essential workers going to high-risk jobs who may also have medically fragile elders in the home. And, since households like these are disproportionately people of color, there is a greater burden that is highly racialized. It all falls at this intersection of systemic inequities."

The letter worked: the Washington State Department of Health, in its decision making on vaccine rollout, prioritized those over 50 in multi-generational homes who can't live independently, or are living with and caring for a grandchild.

In January, King County announced an allotment of \$7 million to set up two vaccination sites in South King County and assemble mobile vaccination teams for homebound elders. Currently, the Seattle Fire Department's Mobile Vaccination Teams host daily COVID-19 vaccination events for the most vulnerable community members.

"We're grateful for community leaders like Trang who lift up issues to organize our community," says Michael Byun, Executive Director of Asian Counseling and Referral Service (ACRS). "Her advocacy effort resulted in changes to the state guidance in terms of priority groups. More importantly, the recommendation that she and others put forward highlighted health disparities that are unique to immigrant and refugee families, and the caregivers who support those family members who are vulnerable. This was very much an equity issue that deeply resonated for Asian Counseling and Referral Service. As an organization focused on social justice, we are here to amplify the voices of our community, especially from individuals who are most impacted by the issues at hand."

Still, immigrant and refugee elders continue to face challenges in accessing the vaccine, reported by families and nonprofits that serve these populations. There are challenges to those especially who cannot understand English or do not have support from an English-speaking caregiver, those without a computer or other technology to look for availabilities or to book appointments, or those who cannot drive or take public transportation to vaccination sites.

Tu and the community collective have deepened their efforts to advocate on behalf of vulnerable elders and caregivers. Volunteers from the group check vaccine sites every day, monitoring and searching

for vaccine availabilities throughout Washington state and alerting community organizations at-large who mainly serve Black, Indigenous, and people of color (BIPOC) communities through emails and texts. These non-profits, in turn, assist their clients in getting vaccine appointments.

The community members behind this effort credit Tu's persistence and determination to bring people together. "I have always believed in the power of numbers, especially when we are coming from a place of racial equity and social justice," says Samantha Yeun, Program Project Manager at Public Health Seattle & King County, one of the letter co-signers who currently cares for three family members at home.

Another member of this grassroots advocacy community collective is Cuong "TJ" Vu (UW '22). As a volunteer at the MBWC and ADRC, Vu hopes to gain experience and help those afflicted with memory loss. Vu, a person of Vietnamese heritage, is also motivated by how much Alzheimer's disease affects the Asian population and other communities disadvantaged by access to care barriers.

After seeing how quickly the appointments were taken up from the vaccine notifications via email, Vu thought of the idea to form text groups so that vaccine leads could instantly reach community organizations. As of early April 2021, their text notifications go out multiple times daily. As vaccine eligibility and demand continues to grow, they have also hosted a webinar on vaccine search tips and tricks so that others may also find vaccine availability for BIPOC communities.

"Increased demand only compounds these barriers if we don't try to level the playing field by assisting our BIPOC elders and those with the greatest barriers to access, especially those with dementia, to provide



Cuong "TJ" Vu

support in finding vaccine appointments and ensuring equitable access at all vaccination sites," says Vu. "With increasing vaccine supplies compared to the very beginning when we started out, it is very satisfying and rewarding to see and share numerous vaccination sites, many more available appointments, and mass vaccination events, especially in areas focused around BIPOC communities."

While a great deal of work remains to render the needs of vulnerable elders and families visible in health systems, Tu is grateful for the response of Washington's state and local leaders, including Governor Jay Inslee, Secretary of Health Umair A. Shah, King County Executive Dow Constantine, and Seattle Mayor Jenny Durkan and their staff. The advocacy collective also appreciated early support with the state advocacy from U.S. Rep. Pramila Jayapal, as well as state legislators: Rep. Sharon Tomiko Santos, Rep. My-Linh Thai, Rep. Rebecca Saldana, Rep. Debra Entenman, and Sen. Manka Dhingra. •

~ Ideas to improve vaccine equity ~ By Cuong "TJ" Vu

- Attend and observe vaccination events to see whether they address the barriers our BIPOC communities experience. Are there enough interpreters? Are there signs pointing out where they can get translation assistance? Are the sites near bus routes, or do elders need to walk long distances from the bus stop? Are there informational brochures about the vaccine translated in different languages?
- Train community organizations serving BIPOC communities on how to find vaccine availability.
- Work with city officials to advocate for earlier notification to BIPOC communities or organizations when vaccine availability opens, or reserve BIPOC-only vaccination hours or days. Have walk-in opportunities that don't require registration or advanced sign-up which is a hardship for many BIPOC elders.
- Ensure interpreters are available at vaccination sites and information is translated in many languages.



A Window of Opportunity

How tai chi classes, held through a pane of glass at a Bellingham memory care community, opened up ways for families to connect with loved ones during the isolation and stress of the pandemic.

By Cuong “TJ” Vu

For more than sixty years, tai chi has been a part of Joe Liao’s life. Growing up in Taiwan, he began studying martial arts at six years old and advanced from student to teacher, eventually to Master after emigrating to the United States and opening up a studio in Burlington, Washington in 1977 to teach tai chi and kung fu. Over the course of the next twenty years teaching his studio classes, Joe welcomed students to learn and practice and cultivate diligence, compassion, balance, integrity, and humility - all with the overarching goal of creating a healthy body and mind.

In 2018, Master Joe’s students expressed concerns about their treasured teacher’s health and worsening short-term memory, and they gathered to figure out what might be happening to him. Joe soon moved into a memory care facility, The Bellingham at Orchard. Laure Brooks, Master Joe’s student since 2004 and now dedicated care partner, grappled with his dementia diagnosis, saying “we still grieve and are saddened that he’s at a memory care facility instead of his familiar studio.” However, she remembered Master Joe’s persistent encouraging motto: “The way’s the way.”

Then the COVID-19 pandemic hit very close to home.

Washington State was identified as the epicenter of a major COVID-19 outbreak, occurring in a long-term facility and quickly spreading to other nursing homes. As a result, visitors to long-term care facilities were banned and family members were forced to communicate and see their loved ones only through windows. Within these facilities, residents were confined to their rooms, group gatherings were cancelled, and meals were delivered to rooms to help control the spread of transmission.

In-person visits and trips that Laure and others had taken with Joe before the pandemic suddenly stopped. He could not longer share his love of tai chi and dance with various communities. With the pandemic forcing him into isolation and lockdown since March, “Joe went into a deep depression and wouldn’t come out of his room, reverting back to speaking mostly his native Mandarin,” Laure recalls. The impacts of lockdown on Joe’s brain health not only created challenges with communication and comprehension, but further compounded feelings of isolation, loneliness, and frustration he and his caregivers were already feeling from the loss of normal connection.

RETURN OF THE MASTER

Knowing Joe’s love of music, Laure had an idea to try to engage and connect with him, even as they had to remain physically separate. She advocated and worked with the memory care facility to have window meetings with him outside his room, waving to him through the glass and dancing along to a boombox. Soon after, Laure enhanced the Orchard’s conference room to make Joe feel like he was in his studio again.

Images courtesy Laure Brooks



She placed familiar objects such as a vase of flowers once located in his former studio and made a playlist of Mandarin music. “My goal was that he could be himself wherever he was, and he would be honored as himself wherever he was, and people wouldn’t be afraid of him,” Laure says. Within this space, Joe transformed back into Master, teaching tai chi classes to facility staff caregivers and residents—and to Laure and former students gathered on the lawn watching him through the conference room window.

Laure and the caregivers at the Orchard have since seen a change in Joe. “He is happier now. He’s singing and coming out of his room like he’s gone beyond the depression and isolation. Now there’s eye contact. There’s corrections; if we have one foot here and one foot there, he indicates how to line up and be balanced, just like he used to.”

TRUSTING THE PROCESS

As word got out about Joe’s tai chi classes through a local newspaper article telling his story and word of mouth spread, Laure worried about the stigma around dementia. How would people react to learning that Joe was now living in a memory care facility? Would people be upset or uncomfortable upon seeing the effects of dementia on Joe, who they had once revered as a Master? He once told people what to do, and no one had really ever told him what to do.

Instead of being fearful, Joe and his son viewed his situation as a way to tell his story, help other people, and continue his lifelong passion of teaching tai chi as a way to improve both physical and mental health. When asked what he thought about him teaching people from the window during the COVID pandemic, Joe responded in English, “it’s wonderful.”

Laure’s initial fears of people withdrawing from Joe or that Joe would be afraid of revealing his dementia to his students or the public quickly resolved. His window tai chi lessons have benefited the community as much as Joe, providing a sense of collective support for one another. Master Joe’s class continually draws an audience, eager to practice tai chi and see Joe continuing to flourish throughout the pandemic.

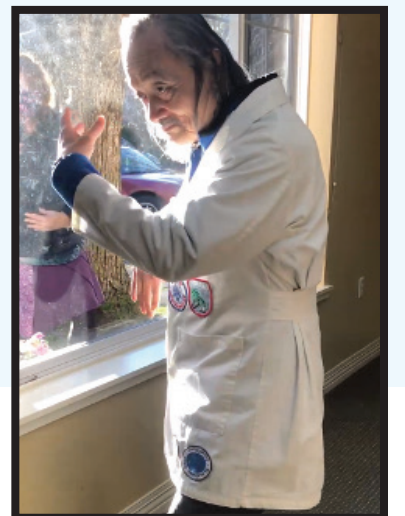
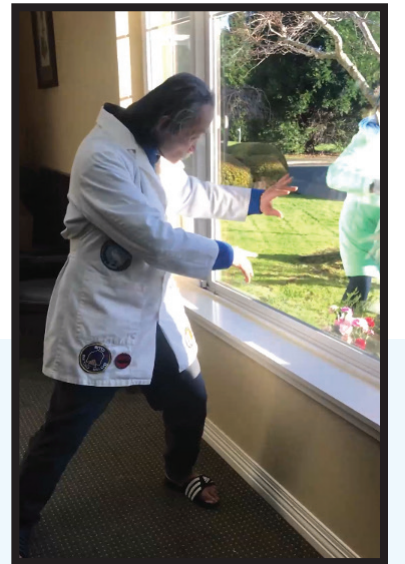
Joe’s gift goes beyond teaching the graceful art form and mind-body connection. He has taught others the importance of silencing and emptying one’s mind in order to drop all our worries and cares and tap into our natural flow. There was a sign in his studio that read: Enter with Silent Mind. He once said that when he empties his mind, he can connect with every person. “I think Joe is helping us realize we can drop our expectations, inhibitions, perfectionism. When I go to class, I realize I am everything that I need and what Joe needs - just by me showing up. There’s this magic moment when you just trust the process.”

DESPITE THE DEMENTIA, JOE STILL REMEMBERS TAI CHI

Even though dementia affects short-term memory, older procedural memories may remain latent and stay intact much longer than people think. Laure believes Joe is still able to teach tai chi, not only because his body remembers tai chi movements, but also because he still has a deep emotional drive to connect with people emotionally.

Dr. Kris Rhoads, PhD, a neuropsychologist at Harborview and UW Associate Professor of Neurology, studies procedural memory—or, deep-rooted memories of how to do things, such as dancing or shuffling cards, for instance. He notes that this form of memory is preserved in people living with dementia for much longer than short-term memories. Short-term memory involves a number of brain structures and networks, including the hippocampus and mesial temporal lobes, and while these frequently change in Alzheimer’s, other structures involved in motor or habit memory, such as the basal ganglia, remain intact. This finding suggests that activities that engage these procedural memories, such as tai chi for Joe, can remain meaningful and productive for those with Alzheimer’s disease and their care partners.

“Long-term and procedural memory frequently remain intact areas of strength, particularly in the earlier stages of dementia but also as things progress,” says Dr. Rhoads. “One of our goals is to lean more heavily on these to use good habits and systems to compensate for short term memory loss. Personally meaningful photographs, videos, news stories or footage, and particularly music from earlier times can provide a conduit to memories and joy for people living with dementia. Care partners can facilitate this by providing the time, space, and occasional cue (such as the name of a place or person) while avoiding quizzing or correcting the person with memory loss and meeting them where they’re at in the moment. This can be a challenging process and requires a healthy dose of compassion for all involved, including oneself.” >>>



People with memory disorders can and want to share themselves, their passions, and creativity with others. “Never underestimate what our loved ones can give us and to be looking for their gift, because their essence is still there,” says Laure. “My advice is to reach out to past and present friends and bring back the memories and the essences of that person.” Laure recommends caregivers to keep trying to connect with their loved ones, even at later stages of dementia. Though they may not be able to communicate through words, they may be able to by a hug or squeeze of the hand. Allow and nurture that process.

WINDOW OF OPPORTUNITY

Connecting with others through tai chi has transformed Joe. It has enabled him to fulfill his life-long purpose to teach and help others learn the ancient art of tai chi for physical and mental well-being. This large picture window not only has now brought him out of the seclusion and loneliness to where he can see the road, cars, as well as life going on, but Laure remembers the empowering change she saw in Master Joe. “I feel like that was kind of where he felt like, ‘Oh, I’m on the stage.’ He’s singing, he’s coming out of his room and he’s gone beyond the depression and isolation.” Definitely, Joe is seeming like the kind of tai chi Master that he always was.

Laure’s main goal was helping Joe reconnect with others. However, she and others would soon realize how much Master Joe was also helping them through the loneliness and disconnection caused by the COVID-19 pandemic. “I think he always was a master, but he was stifled in this new situation and his dementia. He’s taken me to another level, and he’s allowed the people in our class to move to another level of acceptance because they don’t see him fighting ‘what is.’ Seeing him as he is and connecting with where he is now is just so empowering for all of us.” In a way, Joe has reminded Laure and others to accept the current situation the pandemic has created and recognize what we still have rather than what we have lost.

The COVID-19 pandemic and lockdown has had a devastating toll on physical and mental well-being for residents of long-term care facilities, just like Joe Liao. Yet, Laure’s resilience and determined advocacy for Joe changed everything, revealing how caregivers and the community can bring about positive and transformative changes. The window that physically barred them from being together became the very thing that connected them. As Master Joe once taught “the way’s the way,” this window of opportunity has taught us it’s possible to find a way to flourish even in a pandemic that ironically disconnects and connects us all. •

Cuong “TJ” Vu (UW ’22) is a pre-med and Biology major and a Junior at the University of Washington. He is a volunteer at the UW Alzheimer’s Disease Research Center, where he hopes to gain experience and help those afflicted with memory loss. His drive to help stems from witnessing the condition’s toll on his grandmother’s memory and vitality. Once a fierce pillar of strength who fought her way up as a Vietnamese refugee, she earned her Master’s degree to become a Professor of English Studies. Vu is also motivated by how much this disease affects the Asian population, but also other communities disadvantaged by access to care barriers.

As of mid-April of 2021, Master Joe is holding the free window tai chi classes every Monday and Friday at 2pm at The Bellingham at Orchard, 848 W Orchard Dr, Bellingham, WA 98225. All are welcome!



Learn About Project ECHO® Dementia!

The MBWC Clinic’s Project ECHO® Dementia (Extension for Community Healthcare Outcomes) program 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. A brief 15-minute didactic is followed by an hour of case-based learning where everyone at the table is both a teacher and a learner.

All Primary and Allied care providers are welcome. If you support patients living with memory loss or dementia, there is a place for you at the table. To find out more or to sign up, please contact Allyson Schrier, Program Coordinator: allysons@uw.edu

Didactics, case discussions & ongoing mentoring help participants master:

- Best practices around prevention and risk reduction, early detection and diagnosis, communicating a diagnosis, pharmacological and non-pharmacological interventions, deprescribing, management of co-morbidities and behavioral symptoms.
- Billing code accuracy to ensure efficient documentation and appropriate compensation.
- Advance care planning guidelines, managing care transitions, family resources & supports.

The UW Project ECHO® Dementia webpage is a hub for all the information you need to participate in the program.

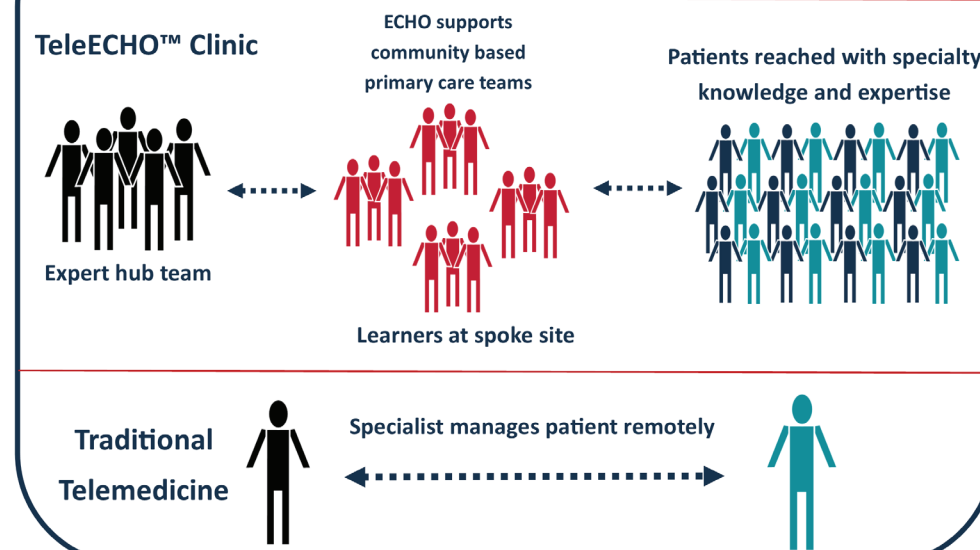
On depts.washington.edu/mbwc/resources/echo, you will find:

- > How ECHO® participants can sign up to deliver a case presentation
- > The 2021 Didactics Schedule
- > All Project ECHO® recorded presentations and slides
- > Forms, Provider Resources, Policy Systems and Level Resources, Family Resources, Articles, and COVID-19 Response Resources

We are proud to partner with the ECHO Institute and local organizations:



ECHO vs. Telemedicine



What's In the Works at the Memory Hub: A Glimpse Behind the Scenes!

Last year, the UW Memory and Brain Wellness Center (MBWC) announced the launch of a new initiative on Seattle's First Hill: The Memory Hub. Bringing together people, programs and partners, the Memory Hub will operate as a vibrant dementia-focused programs and events venue, collaborative workspace and training center. It will be conveniently located just a few blocks from the memory clinic at Harborview Medical Center and beside our partner the Frye Art Museum, welcoming visitors year-round to explore what it means to live well with dementia.

While riding out the past year of COVID, we've had ample time to focus on fine-tuning our plans for the Memory Hub! Meanwhile, with the extended social isolation we've all experienced, a space for community, collaboration and impact has never felt more vital. Here's a glimpse of what's been in the works behind the scenes, as we eagerly await an opportunity to launch:

- Developing virtual programs that we and our partners can offer from the "Zoom room" at the Memory Hub – from support groups to creative arts classes
- Connecting with Memory Hub partners to explore opportunities to partner on virtual programs, such as the new Wellness Wednesdays webinar series with the Alzheimer's Association (www.alzwa.org/wellness)
- Planning for a new statewide dementia-friendly communities learning collaborative housed at the Memory Hub
- Solidifying a generous parking agreement with our neighbors, Murano Senior Living
- Designing a logo, thanks to Memory Hub volunteer Experience Designer Cal Dobrzynski

Stay tuned for a virtual launch, where we'll unveil the website and provide a Memory Hub progress update!

Learn more about the Memory Hub: www.depts.washington.edu/mbwc/resources/memory-hub



The Memory Hub

Thank you to the Memory Hub volunteer Experience Designer Cal Dobrzynski for creating the logo! She captured the community and collaboration at the heart of the Memory Hub.



Introducing the official musical instrument of the Memory Hub! This ukulele was made as gift for Marigrace Becker, Program Manager for Community Education & Impact. MBWC geriatrician Lee Burnside fashioned this instrument out of Hawaiian Koa wood and rosewood. Then, MBWC science writer Genevieve Wanucha hand painted the uke with a wildflower design. See "The Making of Marigrace Becker's Uke": depts.washington.edu/mbwc/content/page-files/Mari_Ukulele2021.jpg



This interactive sculpture will be present in the future memory garden at the Memory Hub. This is a creation of the UK's Acoustic Arts, a company offering handcrafted outdoor musical instruments!

"Ask About Alzheimer's" Middle School Group Offers Peer Support, Connection

By Marigrace Becker, MBWC Program Manager for Community Education and Impact

For many youth, the middle school years can already be a roller coaster of emotions, while exploring personal identity, navigating peer relationships, and bridging roles between child and adult. But having a family member with memory loss or dementia can add another layer of complex feelings into the mix. This past year, two local mother-daughter pairs decided to start an online group to help themselves and others in this situation. The group – Ask About Alzheimer's – brings together students in grades 6 – 8 for a facilitated time of connection, sharing and support.

"We felt that our children were significantly impacted by the changes brought on by Alzheimer's," notes Anne Brown, one of the group's co-founders. "By starting a support group, we wanted to give them the chance to share feelings, ask questions, and openly admit frustrations."

Co-founder Catherine Fleming adds: "My daughter wanted to start this kind of group so she could learn how other kids her age handled life with a grandparent with cognitive impairment. Sharing with peers has helped her understand how better to cope with difficult emotions and stressful situations."

Launched in September 2020 and hosted by the UW Memory and Brain Wellness Center, Ask About Alzheimer's meets by Zoom from 4 – 4:45 p.m. every other Wednesday. Facilitated by Brown as well as geriatric psychiatry resident Aimee McArthur, a typical session includes an ice-breaker, then structured time to check in on how each group member is doing. Periodically, the group invites an expert presenter to attend and address their questions.

Uniquely, Ask About Alzheimer's offers connections to a peer group who can understand the ways their experiences may differ from the average middle schooler. For example, group members may be trying to find new ways to communicate with their family member, adapting activities that they can do together, or providing on-call help with daily caregiving tasks. And while coping with a variety of emotions from grief to anger, they may also be adjusting to the "role reversal" of providing care to someone who typically had cared for them. Finding common ground around these feelings and experiences creates a quick bond.

"Groups like this are so special because of the unique opportunity to surround yourself with people who can relate to what you're going through," notes McArthur. "The members come together to empower and be empowered by sharing their stories, their strengths, and their hardship."

Group member Jordan Kvarda affirms, "One of the main reasons attending this group is so nice is because every single person there knows exactly what you're going through. We don't have to worry quite so much about filtering what we say because we all know this is a really hard situation to deal with."

Do you know someone in grades 6-8 who has a parent, grandparent, or other family member or guardian with memory loss or dementia? They are welcome to give the group a try! Newcomers can join any time and can attend as often as they like. There is no charge to participate. While the group is specifically for middle schoolers, family members can sit in (off-screen) if the student would like.

If a potential group member feels nervous to try it out, co-facilitator McArthur assures: "It can be a bit nerve-racking at first introducing yourself to a new group, but keep in mind that you're among people who are going through similar struggles that you are. This a low-pressure environment where you can share as much or as little as you like. Plus, there are facilitators that help keep the discussion flowing."

Jordan agrees: "Even though it may seem very daunting to put yourself out here and share experiences, it's worth it. It's an amazing way to meet new people who understand your situation." •

Questions about the group can be directed to Marigrace Becker, Program Manager for Community Education and Impact, at 206-744-2190 or mbecker1@uw.edu. Register online, here: <https://tinyurl.com/AskAboutAlz>.

Introducing...The Memory Loss Compass Rose

Towards a New Identity, Hope, and Strength Post-Diagnosis

Chapter 2 of My Journey from Disease into Advocacy



Hello Friends! My name is Kevin Kvarda and you can call me "K-Squared." I have Younger Onset Alzheimer's Dementia, and PPA (Primary Progressive Aphasia). In the months before I got my diagnosis in 2019, I was in agony. I had to pick: 1) FIGHT or 2) FLIGHT with these diseases. I CHOSE to FIGHT and became a Strong Advocate for the CURE for these diseases, and being an Alzheimer's Association board member helps me with my mission. Overall, I am doing very well currently, and because of that, I want to help others and give back in any way I can. I know that someday I might not be able to do this anymore, but until that day, I will keep going STRONG. One day at a time! I want to share about what has helped me in my journey to stay strong and grow after my diagnosis and give encouragement to others.

In last year's Spring 2020 issue of Dimensions and the MBWC website, I [introduced my creation called PRISM](#). This sculpture communicates my wishes to increase strength and hope of patients and all people in the dementia community. But, PRISM was just the beginning. I'm still here! I want to expand the potential of the PRISM.

When the pandemic stopped in-person activities and support groups, I began to think about encouraging messages for people living with a diagnosis like mine. This developed into the idea of a compass and kept growing... into a gift that can help guide you to your True North— your source of well-being, meaning, and identity building. Introducing the Memory Loss Compass Rose!

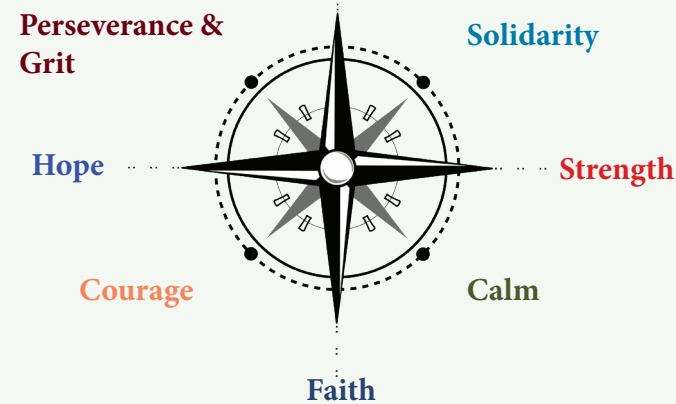
The Memory Loss Compass Rose

The Memory Loss Compass Rose is a GIFT that can guide you toward your new 'True North'. It can help you navigate your journey after a diagnosis, and to embrace change.

Here's how it works:

A person can turn the PRISM because it sits on a rotating platform, or a "flange." Learn about the story behind PRISM from my 2020 article: www.depts.washington.edu/mbwc/news/article/journey-from-disease-into-advocacy. Anyone who needs encouragement can use this Memory Loss Compass Rose, including patients, caregivers, researchers, doctors, and staff of support associations.

"What is Your True North?"



Journey Key

SOLIDARITY People that have Memory Loss NEED others on their side! (Family, Friends, Caregivers, Doctors). When we are connected to others, it is easier to see a path forward. Being connected with others gives you an opportunity to give yourself to others as well as receive friendship.

HOPE What would the world be without Hope? Sometimes, I don't see hope, and later something ALWAYS comes to me or my family. When I feel like there's no hope, I PAUSE what I was doing, and then go to do something else and after that come back to complete.

COURAGE is a blend of solidarity and hope. I believe that everyone has courage in them, BUT without other's support life can be challenging. As we go every day with our Memory Loss, we need USE our tools, such as Solidarity, Hope, family, friends, etc. I believe it is CRUCIAL. Tip: Try to find new friends who know about your Memory Loss and maybe others that don't. Finding new friends will make you more courageous. You WANT to have others on your side who can help with being Courageous.

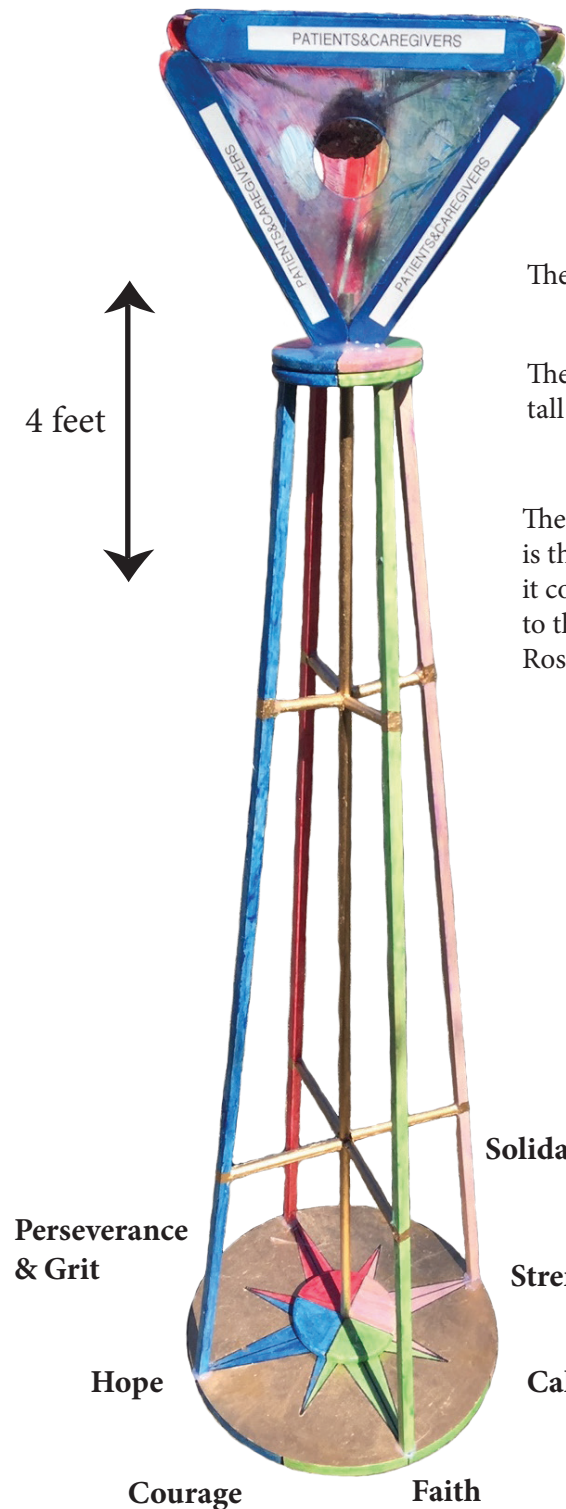
FAITH I believe that Faith is done by work with Courage, Hope, and Solidarity. I believe that Faith is something that YOU should "Opt IN". No one can dictate your Faith...it's personal and wonderful.

STRENGTH What was a moment when you had STRENGTH in your life? For me, it was back when I was a pilot, when I was flying solo or with a student. What was a moment when you didn't have STRENGTH in your life? For me, my wife Norma is strong, so most of the time, I deferred things that I should have been doing to her. What will you do in the future to make you STRONG?

PERSEVERANCE & GRIT Persistence in doing something despite difficulty or delay in achieving success.

CALM "A calm mind brings inner strength and self-confidence, so that's very important for good health." - Dalai Lama

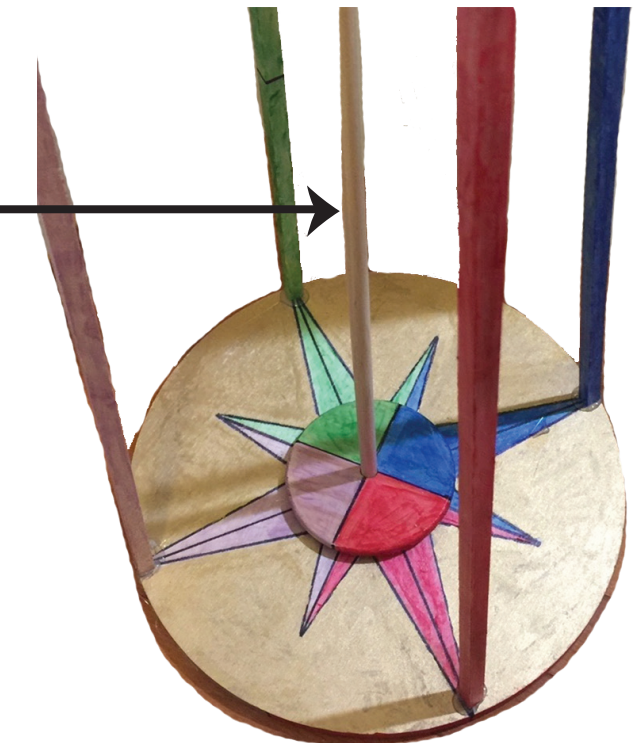
The Memory Loss Compass Rose Comes To Life →



The gold ball inside the PRISM represents humanity.

The PRISM rests on top of tall wooden legs.

The pole in the middle is the "gold fueler" and it connects humanity to the 8-point Compass Rose.

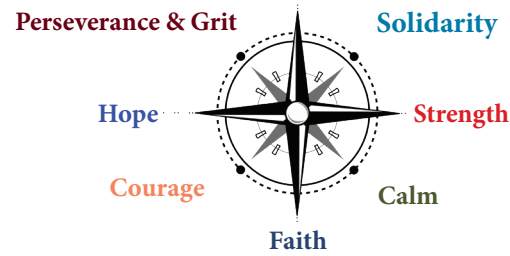


When a user rotates the PRISM above, they will land on different points on the Compass Rose. It is like a matrix of options. The person can explore how these concepts may apply to their journey with memory loss or a challenge. Is there a special recipe (e.g. Courage + Solidarity) that helps define your true North?

Read on for examples of the knowledge you can discover for yourself.

Lessons from The Memory Loss Compass Rose + Worksheet →

What is Your True North?



HOW CAN THE MEMORY LOSS COMPASS ROSE GUIDE YOU? A WORKSHEET

BY KEVIN KVARDA



Leverage your helpers! (Solidarity, Courage, Strength) Take advantage of help that family and friends can offer. For me, word finding, writing, math, lack of comprehension with NEW concepts, etc, take a long time.

Do you like to do things by yourself? Why? _____

Do you like to have others help you? Why? _____

Find and use your higher power to gain strength and knowledge and guide your Mission Statement

(Solidarity, Hope, Courage, Faith, Strength) For example, my higher power is God. My mission statement is "As a STRONG advocate for the cure for Alzheimer's Dementia, Primary Progressive Aphasia, etc. I co-create a world where all these diseases are gone by 2025. How: By working with Doctors, SLP's, others who have these diseases, local agencies (UW MBWC, Alzheimer's Association, etc.), Washington State Capitol, Washington D.C."

What is your higher power? _____

Do you have a Mission Statement? _____

Embrace change (Solidarity, Hope, Faith, Strength, Calm, Perseverance & Grit) We are "different" now. This is a good thing! This is a "new me". Many things are still intact, and I have gained many new friends through my disability and diagnosis. Embracing change IS difficult sometimes. For example, I am not adept with multi-tasking anymore. Conversations with multiple people and loud animals are very challenging most of the time. But I find that I have great stamina with projects, chores, and some days are more normal. Embracing change relies on trust of your self, family, friends, caregivers.

What is your Vision for your self? _____

What Actions can you take to achieve your Vision? _____

Support groups are GOLD (Solidarity, Hope, Courage, Faith, Strength, Calm, Perseverance & Grit) After I got my diagnosis, I wanted to find as many support groups as I could find. It was so EASY to find them, especially here in the Seattle/Eastside/Snohomish areas. My Memory Loss support groups are also my new "rock". We talk about almost anything, and through each meeting we all get 'lifted up' in different ways. It's like a wonderful 'surrogate family'.

What do you need or want to get out of a support group? _____

Compassion (Solidarity, Hope, Courage, Strength, Calm) To recognize the suffering of others and then take action to help. Since my disability, my family (Norma, Riley, Andrew, Quinlan, and Jordan) gives me compassion every day in different ways. Marigrace Becker, Program Manager at UW MBWC gives compassion to EVERYONE, EVERY time she leads meetings!

Have you ever received compassion? How did it feel after? _____

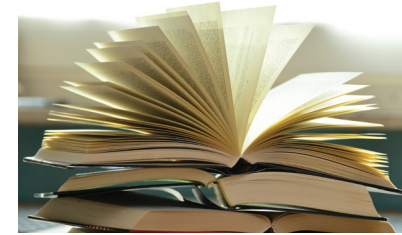
Have you ever given compassion to others? How did it feel after? _____

Giving back (Solidarity, Hope, Faith, Calm) I want to help...one day in the future, I believe that the cure will be found, and I hope I made a dent in the cure in my lifetime. Educate yourself and your caregivers, go to events or Zoom meetings, ask "Hi, can I help?"

What can I do to help, now with my disability? _____

Further Reading & Resources

Kevin's Library



Books in progress:

Mindfulness by Ellen J. Langer

Memory Boosting Puzzles by Charles Timmerman

Us Against Alzheimer's: Stories of Family, Love, and Faith by Marita Golden

A Daybook of Grace: A Year of Devotions to Draw You Near to the Heart of God by Mark Gilroy and Paul Shepherd

A Promised Land by Barack Obama

The Moment of Lift: How Empowering Women Changes the World by Melinda French Gates

Keep Sharp: Build a Better Brain at Any Age by Sanjay Gupta

Kindle books in progress:

Identity Theft: Rediscovering Ourselves After Stroke by Debra Meyerson and Danny Zuckerman

Beating the Dementia Monster: How I stopped the advance of cognitive impairment from Alzheimer's disease by David H. Brown with Vaishali Phatak

Grit: The Power of Passion and Perseverance by Angela Duckworth

Examples of Advocacy in 2020-2021!

- I engaged with our local memory loss community through [virtual Zoom meetings hosted by the UW MBWC](#). The "Virtual Coffee Chats" provide a chance to connect with others in an informal, supportive environment. I led group discussions about the themes included in the Memory Loss Compass Rose.
- I attended a Dementia Action Collaborative meeting. The group meets twice a year, to drive the State Alzheimer's Plan in Washington, as organized by state legislative directive in 2014. I was invited to the meeting by the Alzheimer's Association to represent the perspective of a person living with Alzheimer's disease, as a community stakeholder.
- I participated in the 2021 Alzheimer's Association's virtual [Advocacy Day](#), to represent District 44 (Snohomish). I asked Rep. John Lovick to support \$1.9 million for Dementia Resource Catalyst programs in WA State. These would will improve access to home-based services for people affected by dementia. I also advocated for congress to protect \$1.3 million to continue the work of the [Dementia Action Collaborative \(DAC\)](#). The day brought in 71 participants with a total of 50 meetings. We were the first chapter in the nation to host our advocacy day and have been able to offer tips and advice for other chapters.

The House and Senate released their proposed budgets near the end of March. Here is how our top priorities fared:

- > Dementia Action Collaborative staff and programs: FUNDED in both budgets
- > Specialty dementia care Medicaid rate increase: FUNDED in both budgets; funded at a higher rate in the Senate than the House.
- > Dementia Resource Catalysts: FULLY FUNDED in the Senate at the \$1.914M requested level; PARTIALLY FUNDED in the House.

ACKNOWLEDGMENTS - 2021

- My family of 5, my mother, father, brother, and many relatives in different states.
- Marigrace Becker, Dr. Kimiko Domoto-Reilly, Genevieve Wanucha, Brad Rolf, and James DeLappe (UW Medicine)
- Leslie Kot (UW Speech & Hearing Sciences) and Graduate Student Clinicians: Nicole Campbell, Sarah Harrison, Clarke E. Smith, Ping Lau, Savannah Bailey, Ivy Hoekman, Samantha Bartolo
- Hazel Borden, Katya Strohl, and Peter Newbould (Alzheimer's Association WA State Chapter).
- My 3 spiritual men's groups.

LEARN MORE

- Contact Kevin Kvarda: kevin.kvarda@gmail.com
- Read 5-part article, [Wicked Diseases, Advocacy, and Gifts, Oh My!](#) from Dimensions Spring 2020 by Kevin Kvarda
- Linked In Profile: <https://www.linkedin.com/in/kevinkvarda/>
- Facebook: <https://www.facebook.com/kevin.kvarda>
- Watch Kevin Kvarda's presentation at the MBWC Primary Progressive Aphasia Education Day, on the MBWC video channel here: <https://youtu.be/P-uTsrxx-i0>.
- 'Where is My Identity?' Powerpoint by Kevin Kvarda



The SHARP study is coming to Seattle!

Building a Culturally Engaging Brain Health Program for African American Communities, One Step at a Time

By Alice Mukora and Genevieve Wanucha

“It’s for us. And it’s for the community. It’s for our mind. It’s for our body, the exercise.” This quote is from a Portland resident and participant of the SHARP Study, which stands for Sharing History through Active Reminiscence and Photo-Imagery. This unique study, led by Raina Croff, PhD, Assistant Professor of Neurology at the Oregon Health & Science University School of Medicine (OHSU), combines social engagement and memory sharing during walks around historically Black neighborhoods. The aim of SHARP is to help promote cognitive health for older African Americans, as well as bolster community cohesion through the creation of an oral history archive.

REMINISCING ABOUT WHAT IS NO LONGER

Older African Americans are twice as likely than older white Americans to develop Alzheimer’s disease and other dementias, which may be due in part to the effects of socioeconomic and health-related factors, such as higher rates of cardiovascular disease, which has been linked to higher risk for Alzheimer’s in several studies. Yet, in developing truly engaging and culturally engaging health interventions to test for this population, researchers can face challenges, including overcoming distrust and ensuring that a study gives something valuable back to participants.

SHARP first began back in 2014 when Croff partnered with the PreSERVE Coalition for African American Memory and Brain Health and the Urban League of Portland to conduct focus groups with older Black community members, a study now [published in The Gerontologist](#). Croff and colleagues wanted to learn about the barriers to pursuing healthy aging in Portland, Oregon. Gentrification of the participants’ neighborhoods and its effects dominated the conversation. They had concerns about their ability to age in place comfortably as property taxes rose and long-time trusted neighbors were now being replaced with strangers.

“Many who moved to outlying neighborhoods felt they were less walkable, many felt isolated from their friends, family, and accompanying social life they once had,” says Croff. “The task of reorganizing neighborly relationships felt daunting. They were

reminiscing on the strength of having this close-knit African American community, in which they were hoping to age in place well and with the support of trusted neighbors and friends. So essentially, they are reminiscing what is now no longer.”

These reports of disorientation and isolation illuminated a chance to leverage the power of reminiscence as a potential means of celebrating Black history and culture, while testing whether physical exercise, combined with conversational reminiscence, can help mitigate memory loss or improve cognitive health. The SHARP study was made possible at OHSU by funding by the Centers for Disease Control and Prevention’s Healthy Brain Research Network, the National Alzheimer’s Association, the National Institute on Aging, and Roybal Centers for Translational Research.

Two pilot studies included 21 cognitively healthy seniors and those experiencing memory loss or mild cognitive impairment, as measured through a baseline assessment. Participants had spent at least 10 years of their lives in north or northeast Portland. Three times a week, the members gathered in groups of three and reminisced during mile-long walks through areas once filled with Black-owned homes and businesses but that have become majority white in the last 20 years.

Along the way, a smart tablet prompted the participants with historical photos and news clippings linked to specific sites, and related questions. These “memory markers” spark conversations about people, events, or long-gone landmarks. “They also talked about what it feels like as an older Black adult to be walking through these neighborhoods, and they were processing what neighborhood change means to them,” says Croff. The team recorded the conversations, both for the study and for an oral history archive in progress.



Raina Croff, PhD



Medgar Evers Pool, Seattle, 1969. Courtesy of the Seattle Municipal Archives ID: 31088



Medgar Evers Pool, Seattle, 2003. Courtesy of the Seattle Municipal Archives ID: 178917

The health-related outcomes of the SHARP study reflect significant positive impacts. In the 2017 pilot data, a majority of participants saw a decrease in their blood pressure reading, and all participants rated their mood as better than when they started the program, approximately half had improved scores on cognitive testing after being in the 6-month program, and a vast majority noted they were extremely likely to recommend SHARP to family and friends. The research team found that participants stuck with the program because of the culturally celebratory approach to cognitive health and their interest in the oral history archive. They also appreciated the fact that SHARP provides research opportunities for emerging Black /African American scholars.

Croff’s big goal is that SHARP can be adopted as a program in many other communities. “The long-term vision is that people can download an app with the guided walks, whether they’re in Oakland, or Portland, or Seattle,” she says. “For the oral archive, my vision is for a culturally celebratory resource about cognitive health and Alzheimer’s disease, where we put scary things in the context of our strengths and our resilience.”

BRINGING SHARP TO SEATTLE

At the UW MBWC’s 2020 Collaborating for a Dementia-Friendly Washington: Inspiring Change Conference, Croff presented about SHARP and offered guidance for launching a similar program. The presentation prompted those in the audience to reflect on how this kind of program could be adapted for Seattle’s African American older adults affected by gentrification.

While parts of Seattle have grown more racially diverse over the last decade, other areas have undergone marked gentrification, as young, affluent professionals moved into urban areas. In the Central District and First Hill neighborhoods, owner-occupied home values increased by 90% from 2010 - 2019. Rising property taxes have led the mayor’s Council on African American Elders to encourage the state to increase the threshold for more people to qualify for property tax assistance, and they have had some success since 2019.

Vivian Lee, long-time Seattle resident and member of the Mary Mahoney professional nurses organization, remembers walking every morning to the Central District’s Garfield High School, where 51 percent of students were African American by 1961 (22.8% African American today). “I don’t recognize the Central District right now, with new houses being built and more rentals. Between my mother and brother and I, we knew everybody who was anybody in the Black community. Now, I hear names of people I’ve have never heard of, although I’ve continued to be active in the Black community. People are more dispersed now.”

Rising property taxes, as well as pressure from people offering to purchase houses, can cause stress and confusion for vulnerable older adults, who become at risk of displacement, notes Karen Winston, a Planner with Aging & Disability Services in the Seattle Human Services Department. “Some elders who are still in the Central District are struggling to hang on to their property because of raised property taxes, and a lot of these people are living on fixed incomes.”

“I think the gentrification has hit people hard. Elders are saddened by what used to be and what’s not there anymore,” says Winston. “That’s why I think it’s a good idea to replicate the SHARP program in Seattle—to help preserve memories of these neighborhoods, which is a good exercise for people with memory loss. There is also a huge benefit to walking for brain health and health overall.”

Winston, who acts as the City’s Liaison for the Mayor’s Council on African American Elders, has spearheaded notable efforts to bring culturally tailored dementia awareness and support to African American communities. She has now joined forces with Marigrace Becker of the UW MBWC to lead an effort to pilot the SHARP model in Seattle.

“Our stories, our neighborhoods, our experiences, define who we are,” says Winston. “Those memories are not going to go away, especially if they’re happy memories of family and childhood within the neighborhood. There is the potential for sadness. But I’m not afraid of those bad memories. Sometimes, events that impact a lot of us can bring us together too.” >>>

Winston is a deep source of knowledge on how to connect with the community that a Seattle-based pilot of the SHARP program would aim to serve. She sees a role for Black churches to support the program in the Central District. In 2018, she launched the national Memory Sunday program in the Seattle area, an annual event that equips congregations serving African Americans to provide education on Alzheimer's prevention, treatment, research studies, and caregiver support. "Churches have maintained contact with the elders who have moved or who are still in the community. I do believe that the church is powerful, that people listen and take to heart things that come from the pulpit."

On the SHARP Seattle Planning Committee, co-leaders Karen Winston, MSW and Marigrace Becker, MSW are joined by PI Consultant Raina Croff, PhD and Student Research Advisor Juell Towns, UW Masters of Public Health Candidate. The members of the Planning Team currently include Stephanie Johnson-Tolliver of the Black Heritage Society of Washington; Basia Belza, PhD of UW Health Promotion and Research Center; Tamara Keefe of Seattle Parks and Recreation Department; Dr. Phyllis Gearing-Anderson who chairs the Health Committee for the Seattle/King County Chapter of the National Association for the Advancement of Colored People (NAACP); Dian Ferguson of Central Area Senior Center, and myself, Alice Mukora, UW ADRC/MBWC Volunteer and Data Analyst at the Allen Institute.

"It's an amazing team," says Marigrace Becker. "Working together, we have the opportunity to promote equity around brain health while also lifting up the culturally celebratory work already happening in our area."

We stand on the shoulders of Croff's team in Portland who created and engaged in SHARP and built a valuable resource for other Centers to adapt SHARP for their communities. Importantly, SHARP recognizes and learns from existing programs that highlight Black history in Seattle. These include such groups as Wa Na Wari, a center for Black art and belonging; and the Black Heritage Society of Washington State, which created Rooted in History: African American Heritage Sites Tours of King County/Central District, in partnership with Africatown Media and the Shelf Life Community Story Project.

I'm hopeful that the implementation of the SHARP study in Seattle will be an opportunity to dive into the rich history of the Black community here and celebrate and engage with the culture that may look different now. Being invited to be a part of the planning committee has been such an honor. Advancing culturally engaging work that aims to promote healthy aging and brain health is a critical and crucial goal.

You can learn more about the SHARP Study and its findings at www.sharpwalkingstudy.org

If you have questions about the SHARP Seattle pilot project, please contact Marigrace Becker at mbecker1@uw.edu

Sources:

Balk, Gene. The Seattle area's five most-changed neighborhoods of the decade. *Seattle Times*. March 7, 2021.

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Raina L Croff, PhD, Phelps Witter IV, BS, Miya L Walker, BS, Edline Francois, BA, Charlie Quinn, BS, Thomas C Riley, BS, Nicole F Sharma, BA, Jeffrey A Kaye, MD. Things Are Changing So Fast: Integrative Technology for Preserving Cognitive Health and Community History, *The Gerontologist*, Volume 59, Issue 1, February 2019, Pages 147-157.

Raina Croff, Monique Hedmann, Lisa L Barnes. Whitest City in America: A Smaller Black Community's Experience of Gentrification, Displacement, and Aging in Place, *The Gerontologist*, 2021.

Tate, Cassandra. Busing in Seattle: A Well-Intentioned Failure. *HistoryLink.org*. September 7, 2002.



Karen Winston, MSW



Marigrace Becker, MSW



Alice Mukora



Dr. Angela Hanson, a geriatric physician at the University of Washington and Memory and Brain Wellness Center, is running the MAP research study at the UW Medical Center. MAP is a research study looking at whether metformin can help prevent memory decline for people with mild memory concerns.

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. Taking part in MAP is voluntary and will not affect the care you receive. If you decide to join, you will be compensated for your time.

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

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



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.

Researchers have learned that changes in the brains of people with Alzheimer's disease start as many as 20 years before they notice symptoms like memory problems. During those two decades, a protein in the brain called "amyloid" builds up in people who go on to have memory problems because of Alzheimer's disease. While not all people with amyloid in their brain will develop memory problems, we know that the people who do are at a higher risk for developing the disease.

Participants eligible for the AHEAD Study:

- are healthy adults ages 55-80.
- have not been diagnosed with Alzheimer's disease or another dementia.
- have a study partner, either a close relative or friend, who will participate in one study visit per year.
- 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



The clinical trials of ATH-1017 are evaluating if a new investigational drug is safe and effective in improving symptoms of mild to moderate Alzheimer's disease. ATH-1017 is designed to boost a repair and regenerative pathway for brain cells, promoting brain health and function. ATH-1017 represents a new approach to treat Alzheimer's disease, targeting the root cause of memory decline by repairing the brain cells and rebuilding the brain networks.

You or a loved one may be eligible if you:

- are between 55 and 85 years of age
- have been diagnosed with Alzheimer's disease
- have a reliable support person or caregiver who is willing to participate in study visits, report on daily activities and oversee or help you with taking ATH-1017

Contact: Sarah Simon at 206-744-0446 or ssimon3@uw.edu

Website: www.act-adtrial.com

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

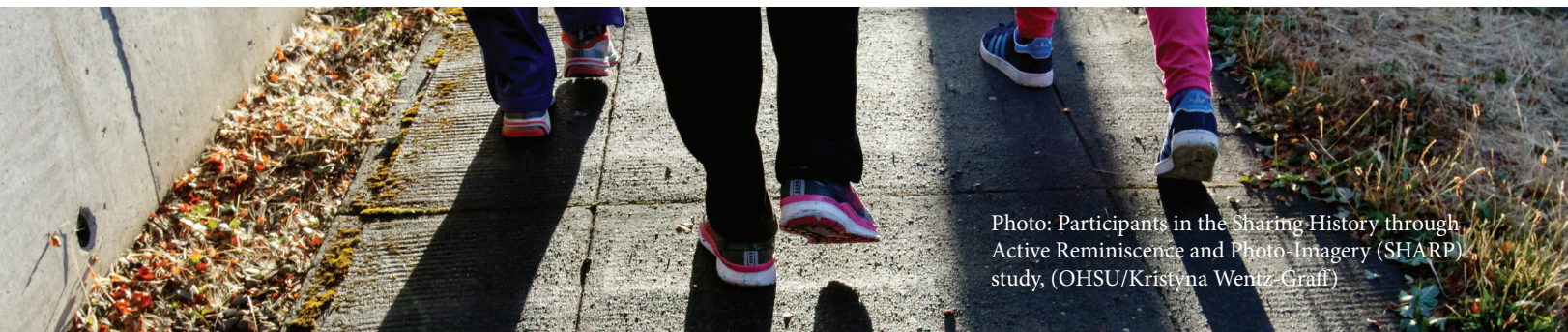


Photo: Participants in the Sharing History through Active Reminiscence and Photo Imagery (SHARP) study, (OHSU/Kristyna Wentz Graff)

Meet Dr. Gary Ferguson: "Lifelong Learner, Wounded Healer"

A Conversation on Traditional Foods, Ways of Healing, and Indigenous Elder Wisdom

Gary Ferguson (Aleut/Unangax) is a Qagan Tayagungin tribal member and licensed Naturopathic Doctor. He serves as Director of Outreach & Engagement, Institute for Research and Education to Advance Community Health (IREACH) at Washington State University. Dr. Ferguson has spent twenty years working across Alaska to address the social, economic, cultural and environmental factors that contribute to the health and well-being of Alaskans. His past positions include providing clinical services to his home region at Eastern Aleutian Tribes and serving as a Director at the Alaska Native Tribal Health Consortium and CEO of the Rural Alaska Community Action Program.

Now, the ADRC welcomes his collaboration with the ADRC Outreach, Recruitment & Engagement Core, where he adds his expertise to our efforts in outreach to American Indian and Alaska Native communities, in partnership with IREACH's Partnerships for Native Health. We spoke with Dr. Ferguson about his life and work to promote the wellbeing of Alaska Native communities through a renewed emphasis on traditional foods and ways of healing, guided by the wisdom and knowledge of Indigenous elders and tribal doctors.



How has your heritage and connection to Indigenous culture influenced your philosophy in life?

I grew up in a southwest part of Alaska in the small Shumagin Islands fishing community of Sand Point. This is a place where a lot of tribal communities came together, along with immigrants from Scandinavia and Russia. Many of us reflect that diversity. We grew up listening to an eclectic mix of Scandinavian schottische and polka music, with people playing accordion. You will see Alaskan Native elders playing the accordion today. It hasn't been picked up as much by the younger generations, but elders still play during some of our gatherings. My guiding philosophy is that we're spiritual beings, living a physical existence, and we're here for a reason. I grew up with that belief as a part of my philosophy, and that perspective translated into my work in healing. I continue to have passion for ceremony in ways that honor our Creator. I look at the importance of our belief systems and how that relates to our wellbeing, through a sense of security and the spiritual knowledge that you're in a place where you can make a difference.

What first sparked your interest in traditional healing and wellbeing?

After I finished undergraduate studies, I worked in my family's electric utility business, and I was also volunteering as an EMT on the Aleutian peninsula. As I was serving these folks in crisis, I started to have these flashes of realization that a lot of the health emergencies were preventable. Those of us who served saw folks die right there in the clinic, and there was unfortunately a lot of vicarious trauma. I knew that emergency medicine was going to burn me out. So, I started studying nutrition and exercise. That change helped shift my priorities, as I looked instead at what can I do from a nutrition perspective, for example, by eating local and traditional foods. I think it is powerful to be connected to your local food system.

I eventually went to medical school to study naturopathic medicine because I was fascinated by our traditional and botanical medicines, and Indigenous ways of knowing and understanding that food is medicine. Hippocrates said, 'Let food be thy medicine and medicine be thy food'—but Indigenous cultures have been saying that food is medicine for thousands of years and, even beyond that, nature, ceremony, and culture are medicine. These tenants from Indigenous cultures informed and inspired me to dig a little bit deeper into these knowledge systems.

Photo: Bald eagle fly-by at Sand Point, AK. Credit: Jeff Fox. Public domain

What are some lessons on healing from Indigenous knowledge systems?

I have had the honor of studying with some of our tribal doctors. Dr. Rita Pitka Blumenstein is one of my close friends and mentors. She is a Yup'ik tribal doctor, now in her 90s. She has helped me over the years to understand the deeper tenets of wisdom that come through tribal doctors and healers. As Dr. Blumenstein says, "We are free to be who we are – to create our own life out of our past, and out of the present. We are our ancestors. When we heal ourselves, we also heal our ancestors – our grandmothers, our grandfathers, and our children. When we heal ourselves, we heal Mother Earth." As we pursue healing, as we are healthier, everything is healthier, because we're all connected. The deep wisdom that comes from Indigenous ways of knowing can help guide us into the future as we face pandemics and environmental challenges.

I'm a lifelong learner, a lifelong healer. And I always like to say 'wounded healer,' because I feel that many of us have gone through much in our lives that have contributed to our ability to be a good healer. Because we've gone through pain ourselves, and we've had trauma, we've had to do the deep work of healing ourselves. And to me, to be a good healer is to understand that in healing, we also heal ourselves.

I'm influenced by the work on culture and resiliency by the late Dr. Gerald Mohatt who served as Director of the Center for Alaska Native Health Research at University of Alaska Fairbanks. The more that you're connected to your culture and where you come from, the more resilient you are. Indigenous youth who are engaged in traditional practices show less risk behavior. From a health systems perspective, that work contributed to my passion around how do we make sure that these traditional approaches to diet and cultural connectedness are available to tribal members.

What is the connection between health and food in the Alaskan community?

After my doctoral studies, I was blessed to return to Alaska, where we have 229 federally recognized tribes, and a diversity of Indigenous knowledge. I worked at the Alaska Native Tribal Health Consortium and consulted with the Tribal Doctors in the Traditional Healing program at Southcentral Foundation. We had the honor of deeply engaging Alaska Native Elders through a research project called Helping Ourselves to Health. This was a USDA National Institutes of Food and Agriculture-funded research program on obesity and connection to changes in diets within the Yup'ik and Cup'ik population in southwest Alaska.

We found that traditional foods contributed to a huge amount of the nutrition that folks got in the region, even though it was a small part of their diet, because many folks had been embracing Western foods as primary due to the western influences of colonization. Part of the reason that many of us are seeing disease is a departure from some of these traditional foods and culture that promote wellbeing.

As we held focus groups with Elders in the Yukon-Kuskokwim Delta, they shared that they saw the need for more modern ways to prepare traditional foods and engage our younger generations, because many of them are giving up our language and our traditional foods. They asked, 'How do we engage them?' They

noted that the Food Channel, and various other media, are really popular. So that gave us the building blocks to launch the 'Store Outside Your Door' webisode series to promote the knowledge and use of traditional foods in different communities in Alaska. Each video, available on YouTube, teaches how to harvest and prepare a nutritious traditional dish with a contemporary twist and science-based knowledge.

What is your perspective on how traditional ways of healing can be incorporated onto Western medicine?

A good chunk of our pharmacopeia in western medicine are analogues of compounds from plants that were used by Indigenous peoples all over the world. I think sometimes we don't really think of that enough when it comes to intellectual property. For example, the breast cancer drug tamoxifen comes from taxol, which comes from the Pacific Yew tree. This tree was long used for medicinal and spiritual purposes by the indigenous peoples of the Pacific Northwest, Southeast Alaska, and Canada. So, I feel like we have an opportunity moving forward to honor this wisdom in health care. Like, how do we respect these medicines, and how do we connect with the deeper knowledge behind that medicine, rather than just the key pharmaceutical constituents? Is there a ceremony with this medicine connected to deep cultural values? We could take more of a holistic approach in our health systems, and especially health systems serving Indigenous Peoples.

How are traditional cultural values around caring for elders, and respecting the wisdom of elders, being reflected in this current moment?

I was always close to my grandparents. It was the most beautiful thing to be able to help coordinate care for my grandmother Marina Gundersen in the last year of her life after a stroke, and then for my grandfather Emil Gundersen. He was an amazing long term cancer survivor who had a clear mind up until the day he died at 89. As I was spending time with my grandparents and seeing their needs, I looked around and started to bring my awareness to the fact that not all elders have social support services, family systems are fractured, and many are suffering. To me, it just went in the face of our cultural values and fueled my advocacy. I joined the Board of Directors of Access Alaska, which offers services to help Alaskans with disabilities to live independently. It was just a no-brainer. In the Tribal Health System, long term care isn't covered by Indian Health Service. And some of our tribal health agencies are doing amazing programs, but there are still many gaps. I feel that the more we can age in place, and have resources to do so, the better we can honor and care for our elders. Not every family can have their elder stay at home, because they just don't have the resources, or it's not safe for the elder or for the family. But if an elder needs to go into a skilled nursing facility or a nursing home, we need to have facilities that are more human, with more visiting and spirit. It's heartbreaking to see elders in some of the facilities that can be so sterile and devoid of cultural foods or practices.

But, recently, COVID has highlighted the deep respect our communities have for elder wisdom. A lot of communities have taken COVID very seriously and protected our elders with limiting travel and wearing masks. Some of our rural areas have no COVID cases and are close to 100% vaccinated. >>>



Emil Gundersen, Gary Ferguson's late grandfather. Courtesy: Gary Ferguson

I think the lessons from the past informed us here. In pandemics and epidemics that we've experienced over our history, we had communities where sometimes only one or two people survived.

Elder wisdom is the way that culture gets perpetuated, and even one extra year of having an elder alive and vital in the community, means that young people and others get to engage that elder for that period of time. We value elders because they're our source of wisdom, knowledge, and cultural perpetuity. They hold wisdom on how to hunt, fish, and gather, how to understand the weather systems, and how generations have survived through oral storytelling. Elders help us to live healthy, vital lives, because they help inform us. They bring a healing energy to a room.

What traditional healing approaches are most helpful for elders living with dementia?

When I think of dementia and some of the agitation that can happen, I think of some of the Indigenous ways of healing that can really help a person calm down. Simple hand or foot massage, with good intention and energy, can be profound for elders. I think a lot of elders respond well when you have just that time and presence and put hands on somebody in a safe way, with permission. And, and having healthy touch that allows them to be more grounded. It comes down to just being present, connecting with somebody, and spending the time with them. I think that touch is an important part of healing. And, I feel like elders especially don't get enough touch.

I think that creating a comforting and caring environment really helps elders with dementia to be as high functioning as possible, and have those clear, lucid moments that are extra special. I feel like often they don't remember it the next day, but I think on a spiritual level, they really do. There's something very special in your relationship and connection with an elder with dementia, even if you don't get back an acknowledgment. The gift is the

relationship. It's part of just showing up, of being respectful.

A way of respecting elders living with dementia is saying, "That's so interesting." Or, "Yes, I remember that," instead of, "Hey, I've heard that before." We allow them to tell their stories. Lately, I've been playing music for my dad, who has early Alzheimer's, and it brings forth such great memories and rich storytelling. I know what kind of music he likes because he was a musician, and it's been so fascinating and fun to evoke those memories. And it's also been emotional for him. There is a sense of loss and grieving, as he revisits traumas. It's profoundly healing for him to share his stories and talk about his life. I feel like that's the gift that I also receive by spending time with him. •

This interview was conducted by Genevieve Wanucha, MS, Science Writer, UW ADRC/Memory and Brain Wellness Center

MORE INFORMATION

- Dr. Gary Ferguson was interviewed by Rhonda McBride at KTOO for "Alaska Native traditions: lighting the way through the darkness of COVID." The segment highlights ways we can improve our resiliency during this difficult time. <https://www.ktoo.org/2021/01/26/where-is-juneau-on-the-covid-journey/>
- Store Outside Your Door: Dr. Gary Ferguson Speaks at TEDx Anchorage 2012 : <https://youtu.be/GMezsQkFfyg>
- Dr. Gary Ferguson created a digital story about his grandfather, Emil Gundersen. He was an amazing long term cancer survivor who had a clear mind up until the day he died at 89. Watch: https://youtu.be/sLej_huYzdw

SAVE THE DATE!

Collaborating for a Dementia-Friendly Washington: Expanding Possibilities

A **virtual conference** promoting the growth of dementia-friendly communities in our state

Registration opens July 30: www.tinyurl.com/DementiaFriendlyWA2021

PRE-CONFERENCE "HAPPY HOUR"

Monday, September 13 | 4 - 5 p.m.

Experience "Dementia Friends," a 1-hour info session that you can use to bring dementia awareness to your communities

TWO-DAY VIRTUAL EVENT:

Tuesday, September 14 | 9 a.m. - 12 p.m.

Wednesday, September 15 | 9 a.m. - 12 p.m.

- **CONNECT** with others who share your passion for raising dementia awareness, challenging stigma, and empowering people with memory loss to remain active and connected within the community
- **BE INSPIRED** by innovative programs and initiatives across the state and nation
- **DISCOVER** steps to make your own community more dementia-friendly

Organized by the UW Memory and Brain Wellness Center, on behalf of the Washington State Dementia Action Collaborative, with primary funding provided by the Aging and Long Term Support Administration, and with a planning committee made up of advisors from across the state.

Questions:

Marigrace Becker mbecker1@uw.edu 206-744-2190

A dementia-friendly community is a town, city or county committed to the full inclusion of people with dementia and their families in community life.

Who should attend?

This conference is for anyone who wants to take action to make their own community more dementia-friendly, including people with dementia, caregivers, and people who work in a variety of public settings:

- Aging and senior services
- Arts and culture
- Chambers of commerce
- City government
- Community centers
- Cultural associations
- Faith communities
- Libraries
- Neighborhood groups
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UW ADRC
Harborview Medical Center
Box 359791
325 9th Ave
Seattle, WA 98104-2499

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