

# DIMENSIONS

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



## Home Is Where the Art Is

Can a Creative Indoor Environment Help Loved Ones Age in Place?

- **Building a Platform for Protein Therapeutics**
- **My Journey from Disease into Advocacy**
- **The Power of an Active Lifestyle to Boost Cognitive Resilience, Even for Those at High Risk**
- **Aging with Pride: Improving the Quality of Care for LGBTQ Older Adults**
- **“Sweeping Aside the Clouds:” The Wisdom Behind Indigenized Health Interventions for Elders**

## Hello readers!

The UW ADRC and its associated clinical and educational programs at the UW Memory and Brain Wellness Center are pleased to bring you Dimensions for Spring and Summer 2020!

As we go to press, our community finds itself in uncharted territory as it pulls together to counter the novel coronavirus pandemic. We hope this issue provides you with interesting reading material during this time of increased social distancing. As you will see, we continue our work to advance understanding of Alzheimer's disease and related disorders, on a foundation of community trust and support.

These pages feature timely topics, such as new findings on how staying active, with indoor hobbies or light exercise, can boost the brain's resilience. Our clinic team offers their favorite brain-healthy things to do in this time of social distancing. We have a story on the researchers creating protein therapeutics for Alzheimer's disease and highlights of recent research and grants. The latest installment of our Indigenous Aging Brain Health Series features Becky Bendixen, the creator of Wisdom Warriors, who adapts health interventions, such as Tai Chi, to work better for elders of different cultural and tribal backgrounds. As always, 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, Ms. Charlotte Merritt, the Sky Valley Whirlwinds, 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!

Questions or feedback about Dimensions is always welcome. Email: [gwanucha@uw.edu](mailto:gwanucha@uw.edu)



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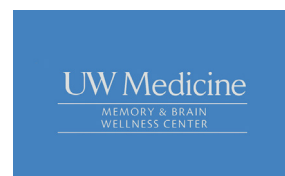


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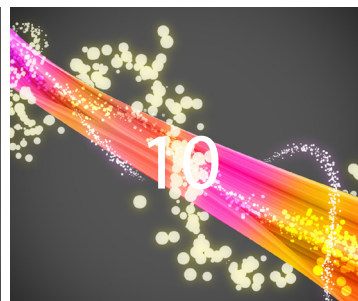
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**DIMENSIONS** The University of Washington Alzheimer’s Disease Research Center (UW ADRC) is affiliated with the UW Medicine Memory and Brain Wellness Center (MBWC) and the Veterans Affairs Puget Sound Health Care System (VA). The UW ADRC has been 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 a precision medicine approach. The UW ADRC is also supported by the Friends of Alzheimer’s Research, the Ellison Foundation, the Richard M. and Maude Ferry Charitable Foundation, the Paul V. Martinis Estate, the Anderson Foundation, Ms. Charlotte Merritt, the Sky Valley Whirlwinds, and members of the public.

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# Featured Publications

## New Genetic Targets

**Activity of the poly(A) binding protein MSUT2 determines susceptibility to pathological tau in the mammalian brain.** Wheeler JM et al. *Science Translational Medicine*, December 2019 // Jeanna Wheeler, Pamela McMillan, Timothy J. Strovas, Rebecca L. Kow, Patricia Szot, Linda Robinson, Chris Guthrie, Aleen Saxton, Nicole Liachko, Murray Raskind, Elaine Peskind, C. Dirk Keene, Thomas Bird, Brian Kraemer

In the wake of recent disappointments over clinical trials targeting amyloid plaque build-up in Alzheimer's disease, researchers are focusing more attention on misfolded tau protein, another culprit in brain diseases that cause several forms of dementia. New research finds that targeting abnormal tau through the suppression of a gene called MSUT2 (mammalian suppressor of tauopathy 2) shows promise.

Tau, like amyloid protein, is another substance that builds up in the brains of people developing Alzheimer's disease, as well as types of frontotemporal degeneration. However, clinical trials targeting tau have been far less numerous in part because tau-targeted drugs have been hard to find.

In this study, researchers concluded that suppressing MSUT2 might protect people from Alzheimer's disease, as long as the RNA binding protein PolyA Binding Protein Nuclear 1 (PABPN1) is not depleted by the treatment. MSUT2 and PABPN1 normally work together closely to regulate the biology of tau in the brain, so fooling with PABPN1 would have negative consequences. The researchers knocked out MSUT2 function in mice, thereby preventing the formation of the tau tangles that kill off brain cells. This intervention lessened learning and memory problems as well. While examining autopsy brain samples from Alzheimer's patients, the researchers found that cases with more severe disease lacked both MSUT2 protein and its partner protein, PABPN1. This finding suggests that neurons that lose the MSUT2 -PABPN1 protein partnership may die off.

Moreover, mice lacking MSUT2 but possessing a normal complement of PABPN1 were strongly protected against abnormal tau accumulation and the resulting brain degeneration. The researchers concluded that the key to helping people with abnormal tau buildup is blocking MSUT2 while preserving PABPN1 activity.

## Medications and Brain Health

**Beliefs about benefits and harms of medications and supplements for brain health.** Marcum et al. *Preventative Medicine Reports*, January 2020 // Zachary Marcum, David Barthold, Oleg Zaslavsky, Eric Larson, Shelly Gray

In a study published in January, researchers published a survey to better understand the general public's perceptions of medications and supplements for brain health and dementia risk. The researchers received 1,661 responses to the web-based survey, which largely came from white women between the ages of 51 and 70.

The survey asked questions about the relevance of vitamin E, ginkgo biloba, hormone treatments, fish oil, statins, and sleep aids to brain health. A substantial number of people viewed the listed supplements positively, but the scientific evidence does not indicate that any are valid treatments for dementia. The supplements all have shown promising effects in epidemiological evidence. However, every single supplement listed in this survey has been rigorously tested in randomized clinical trials, and none of them produce any differences in reducing the development of dementia when compared to the use of a placebo. Further research is needed for scientists to understand the circumstances, doses, and types of drugs in this class that can be helpful or dangerous.

The researchers behind the survey believe that healthcare professionals and patients should improve efforts to inform the general public about supplements, pharmaceuticals, and brain health, and the Memory and Brain Wellness Center will continue to deliver important updates to our patients and readers.

**Read:** Fish Oil and Seafood for Brain Health: What's the Evidence? by Dr. Angela Hanson, MD: <https://tinyurl.com/t2vnfrv>

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\*Only UW-affiliated researchers are listed

## Risk and Resilience

**Exceptionally low likelihood of Alzheimer's dementia in APOE2 homozygotes from a 5,000-person neuropathological study.** Reiman EM et al. *Nature Communications*, February 2020 // C. Dirk Keene, Eric B. Larson, Paul K. Crane, Walter Kukull

Most people with Alzheimer's-type dementia have the late-onset form of the disease, in which symptoms become apparent in the mid-60s or later. The causes of late-onset Alzheimer's are not yet completely understood, but they likely include a combination of genetic, environmental, and lifestyle factors that affect a person's risk for developing the disease. Researchers have not found a specific gene that directly causes the late-onset form of the disease. However, variations in the apolipoprotein E (APOE) gene on chromosome 19 do influence risk, but only for people of European ancestry.

Everyone has two copies of the APOE gene, and each copy can be one of three different variants, called alleles (E2, E3, or E4). In the human populations studied so far, each allele seems to produce a different level of risk for a person developing Alzheimer's disease, with the E4 allele linked to higher risk, and the E2 allele associated with lower risk. Having two copies of E4 puts someone at higher risk than only having one. The purpose of this study was to see if the protective effects of the E2 allele are also additive – whether two copies of E2 are better than one.

Researchers looked at the odds that someone with a combination of different APOE alleles would develop Alzheimer's disease vs. the odds that they would not. They created odds ratios to measure the likelihood of an Alzheimer's outcome with different genetic combinations in a pool of 5,000 clinically diagnosed and autopsy verified Alzheimer's dementia cases and controls.

The study found that the odds of developing dementia due to Alzheimer's disease for individuals with two copies of E2 was lower than for those with two copies of E3 or one copy of E2 and one copy of E3, and their odds were much lower compared to those with two copies of E4. When the researchers narrowed the analysis to generate odds ratios only from individuals who had definitive autopsy confirmation of Alzheimer's disease, the trends for the protective effect of E2 were even stronger. This research highlights the importance of discovering how different variants of the APOE gene influence the development of Alzheimer's disease. Finding and targeting the factors connected to this influence could be groundbreaking for the treatment and prevention of the disease.

## Alzheimer's and Epilepsy

**Loss of presenilin 2 age-dependently alters susceptibility to acute seizures and kindling acquisition.** Beckman M et al. *Neurobiology of Disease*, December 2019 // Megan Beckman, Kevin Knox, Zachery Koneval, Carole Smith, Suman Jayadev, Melissa Barker-Haliski

Patients living with Alzheimer's disease show higher rates of spontaneous seizures than the general population, but people with rare early-onset Alzheimer's disease are at particularly high risk. One study reported that 29% of patients affected by a mutation in the presenilin 2 (PSEN2) gene have at least one seizure within five years of diagnosis. So, researchers want to understand how alterations in normal function of this Alzheimer's risk gene impacts susceptibility to seizures across a lifespan.

The researchers studied mice lacking a functional PSEN2 gene as their preclinical model system. In one part of their study, they used corneal kindling, a method to trigger chronic brain hyperactivity associated with epilepsy (a state of increased susceptibility to seizures) in the mouse brain. The kindling model is often used to study epilepsy and is commonly used to discover antiseizure medications.

The investigators found that younger, but not older, PSEN2 knockout mice took significantly longer than normal mice to develop a "kindled state," meaning that they took longer to develop "epilepsy". However, once the young mice had established an epileptic state, their seizures were of longer duration than those of aged mice. This finding suggests that there is an age-related change in the brain that makes early life seizures more severe in mice with loss of normal PSEN2 function.

This study demonstrates that the loss of normal PSEN2 function may contribute to formation of an epileptic network in the brain and alter the risk for acute seizures seen in patients with Alzheimer's disease. This new collaboration between investigators with expertise from the Alzheimer's and epilepsy fields creates new opportunities to identify novel molecular targets for seizures in Alzheimer's disease, as well as to clarify the mechanisms of seizures in people living with dementia.

# Building a Platform for Protein Therapeutics

By Franklin Faust

Like pieces of a biological jigsaw puzzle, proteins and other molecules have different shapes and edges that determine how well they fit and attach to one another. A protein's microscopic structure dictates which molecules it sticks to and how it interacts with them, which in turn determines whether the protein works to keep us healthy, or conspires to make us sick.

Historically, researchers have tried to counter disease-causing proteins and viruses by searching nature for therapeutic molecules that can bind to them and change their function. But the right piece for the puzzle doesn't always exist in nature – especially for solving modern diseases of aging, such as Alzheimer's, which involve multiple proteins and complex pathways of progression. "Evolution hasn't prepared proteins to solve problems like Alzheimer's because people didn't live long enough to develop it," says Dr. David Baker, PhD, Professor of Biochemistry and Director of the UW Institute for Protein Design (IPD). Now, researchers at the IPD are thinking outside of the box. They're building a protein design platform to solve the puzzles of treating neurodegenerative disease with new protein therapeutics.

## DESIGNER PROTEINS

Dr. Baker conceived the first edition of a protein design software called Rosetta in the 1990s. It has developed into the premier tool for a new technique called *de novo* protein design, which refers to the creation of new proteins to solve specific problems in medicine and engineering. Rosetta's algorithms boil down decades of protein-interaction science to help scientists transform a digitally rendered, non-functional protein scaffold into a new protein whose precise shape is predicted to fit a target structure.

The next step is to test out Rosetta's predictions about a designer protein in the laboratory. First, researchers inject yeast cells with synthetic genes that code for the new, designer protein. The yeast cells produce the protein and are placed in a test tube containing the designated biological target, and fluorescent tracers allow researchers to visualize the strength and stability of the binding.

## A STICKY SITUATION

In a UW Alzheimer's Disease Research Center (ADRC)-funded project, IPD researchers used these methods to build proteins that could bind to amyloid beta, a toxic protein linked to Alzheimer's disease, and prevent it from converting to more neurotoxic forms. But binding to amyloid beta proved particularly difficult. "Amyloid beta is a very sticky molecule," says Dr. Nihal Korkmaz, Post-Doctoral researcher at the IPD. "Like oil in water, the amyloid sticks to itself and forms clumps. To interact with that target successfully, our designer proteins needed a suitably sticky structure. The problem became that the proteins we designed would stick to themselves before they could stick to the amyloid." This challenge caused researchers at the IPD to rethink their strategy.



David Baker, PhD. Credit: Ian C. Haydon / Institute for Protein Design

"We decided to take a step back and explore the general barriers to designing proteins therapies for neurodegenerative conditions," says Dr. Gaurav Bhardwaj, PhD, Assistant Professor in the UW Department of Medicinal Chemistry, School of Pharmacy, and Principal Investigator at the IPD. For Korkmaz, that meant transitioning away from amyloid beta to design binders for lower hanging fruit – simpler target proteins that participate in the mechanisms behind Alzheimer's disease. >>>

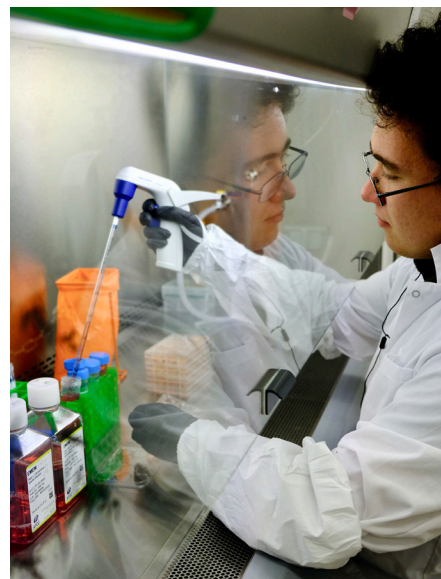
Korkmaz's continued efforts are piecing apart which design features make or break protein binding, and that's producing higher success rates. "If we can better establish the fundamental principles behind targeted binding, we should be able to translate that success to not only amyloid beta, but to all other disease targets we can imagine," says Korkmaz. Her work is foundational to developing proteins that can bind strongly and specifically to neurodegenerative targets, but to reach those targets, they'll need to enter the brain.

### SLIPPING PAST THE BRAIN'S SECURITY

The blood-brain barrier is the brain's first line of defense, and, unfortunately, it can't tell the difference between a toxic pathogen and a neurodegenerative disease treatment. If a protein therapeutic is too big, it won't be able to cross the blood-brain barrier on its own. If the therapeutic is too small, it won't bind selectively to its biological target when it gets there.

Bhardwaj bet on peptides, which are short chains of amino acids. He thought peptides could be the perfect size to pass through the blood-brain barrier without sacrificing the specificity of their binding, and he was right. "We developed precisely structured, cyclic peptides capable of crossing the blood-brain barrier," says Bhardwaj. "That proved we could design peptides to bind specific target structures and actually get them into the brain." Bhardwaj's work is a proof of concept for small protein therapeutics, but IPD researchers expect that larger protein therapeutics will be needed to bind certain disease targets.

Dr. Danny Sahtoe, Postdoctoral researcher at the IPD, hopes to leverage a blood-brain barrier transport protein called transferrin receptor to smuggle bigger protein cargo into the brain. Transferrin receptor only shuttles nutrients and signal molecules of a specific shape, but Sahtoe is working on a loophole. "We've developed a mini-protein that binds transferrin receptor and crosses a model of the blood-brain barrier," says Sahtoe. "If we can fuse a protein therapeutic to that mini-protein shuttler, transferrin receptor could carry larger protein therapeutics into the brain."



In order to develop effective protein therapeutics that can take advantage of these new delivery methods, IPD scientists say they need more biological targets in neurodegenerative disease pathways for their experiments. Fortunately, the UW ADRC can help. "The new Imaging and Biomarker Core aims to map out the molecular mechanisms involved in neurodegenerative diseases to develop targeted biomarkers," says Thomas Grabowski, MD, Professor of Radiology and Director of the UW ADRC and UW Memory and Brain Wellness Center. "That puts our Center in a great place to supply IPD researchers with curated lists of neurodegenerative disease targets that they need to move forward." Together, our Centers hope to solve the many puzzles of neurodegenerative disease and bring a new generation of protein therapeutics into the clinic. •

*\*In this online version of Dimensions, the term "transferrin" has been corrected to read "transferrin receptor."*

### SOURCES

- Bhardwaj G et al. Accurate de novo design of hyperstable constrained peptides. *Nature*, 2016.
- Marcos E et al. De novo design of a non-local  $\beta$ -sheet protein with high stability and accuracy. *Nature Structural & Molecular Biology*, 2018.
- UW Institute for Protein Design [www.ipd.uw.edu](http://www.ipd.uw.edu)

## NEW GRANTS AND FUNDING

A platform for cell type-level transcriptomic, epigenomic and spatial interrogation of Alzheimer's disease (NIH, U19) [Ed Lein](#), [Thomas Grabowski](#), [C. Dirk Keene](#), [Eric Larson](#), [Paul Crane](#)

'Protection from pathological tau by activation of the ER unfolded protein response (NIA R01) [Brian Kraemer](#)

Understanding the functional impact of cumulative genetic risk in Alzheimer disease (NIH, RF1) [Suman Jayadev](#)

Characterization of a human in vitro blood-brain barrier model to study the effects of systemic aging on responses to Alzheimer's disease effectors (NIH, R21). [Michelle Erickson](#)

Modulation of AD by HSV Infection (NIH, R01) [Martin Darvas](#), [Christine Johnston](#)

Molecular mechanisms of synergistic TDP-43 and tau proteotoxicity in Alzheimer's disease (NIA, K08) [Caitlin Latimer](#)

Lipid MRI Pilot Study (Catalyst Grant) [Angela Hanson](#)

2020 Healthy Aging Program to further research on cognitive decline and neurodegenerative disease (Brown Foundation) [Elizabeth Rhea](#), [Michelle Erickson](#), [Brian Kraemer](#)

Antihypertensives and the aging brain (NIA, K76) [Zachary Marcum](#)

**The UW ADRC is excited to announce three newly funded Weill Neurohub projects. In collaboration with UC Berkeley and UC San Francisco, we will tackle big challenges in Alzheimer's and related disorders research and brain imaging!**

FOUNDATIONS AND INITIAL NEUROIMAGING APPLICATIONS OF NEXTGEN 7T MRI. [UCB: Chunlei Liu](#), [David Feinberg](#); [UCSF: Pratik Mukherjee](#); [UW: Thomas Grabowski](#).

AN INTEGRATED, PATIENT-FOCUSED, AND CELL-BASED APPROACH TO DEVELOP NOVEL THERAPEUTICS FOR ALZHEIMER'S DISEASE AND RELATED DISORDERS. [UCSF: William Seeley](#), [Lea Grinberg](#); [UCB: Michael Rape](#), [Jennifer Doudna](#); [UW: C. Dirk Keene](#), [Suman Jayadev](#), [Jessica Young](#)

WEILL NEUROHUB DATA AND ANALYTICS CENTER [UCSF: Roland Henry](#), [Shrivshankar Sundaram](#); [UCB: Kris Bouchard](#), [Bin Yu](#); [UW: Bing Brunton](#), [Thomas Grabowski](#)

Read about these projects at: [www.weillneurohub.org/news](http://www.weillneurohub.org/news)

## WEILL NEUROHUB

## WEILL NEUROHUB LAUNCHES WITH INVESTMENTS IN FOUNDATIONAL PROJECTS

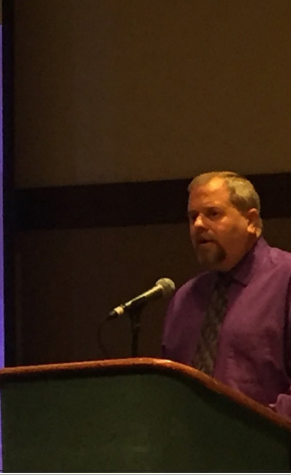
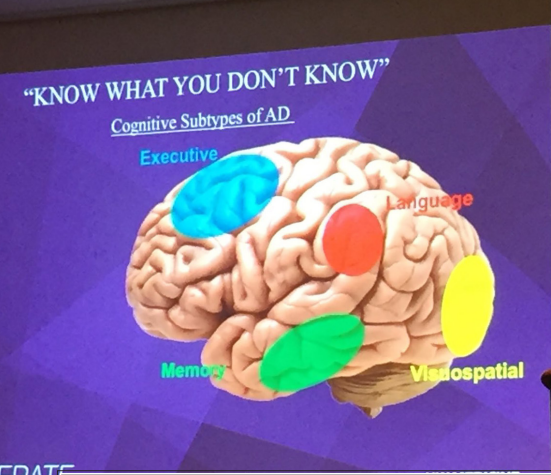
The Weill Neurohub launched in November 2019 with a \$106 million gift from the Weill Family Foundation. The network brings together neuroscience communities at UC San Francisco, UC Berkeley, and the University of Washington and draws on the power of Lawrence Berkeley National Laboratory (LBNL) and Lawrence Livermore National Laboratory (LLNL) to answer some of the toughest questions about the brain and find effective therapies for the millions of people who suffer from neurological and psychiatric illnesses. By forging interdisciplinary partnerships and harnessing resources collaboratively, the Weill Neurohub will accelerate neuroscientific and clinical breakthroughs.

Weill Neurohub Awards  
APPLICATION OPEN CALL

An open-call application process for Weill Neurohub awards will begin later this spring, with the first grants being made in January 2021. Faculty members, postdoctoral fellows, and graduate students from the neuroscience communities at all three institutions will be invited to apply. The awards committee will consider proposals for highly innovative, cross-institutional projects and "high-risk/high-reward" explorations.

[www.weillneurohub.org/rfp](http://www.weillneurohub.org/rfp)





## 8th Annual Adult Changes in Thought Symposium

Call for abstracts and proposals

This summer, the 8th annual ACT Symposium will highlight aging and dementia research from the long-standing Adult Changes in Thought cohort and affiliated studies (PIs Eric Larson and Paul Crane). The theme of this year's symposium is "Bridging population science and human biology to understand brain aging and dementia risk".

The call for abstracts and proposals is now open! Due date: June 1, 2020, 9pm Pacific.

Please submit here: <https://actsymposium.wufoo.com/forms/s5z3gvh1p00t8o/>

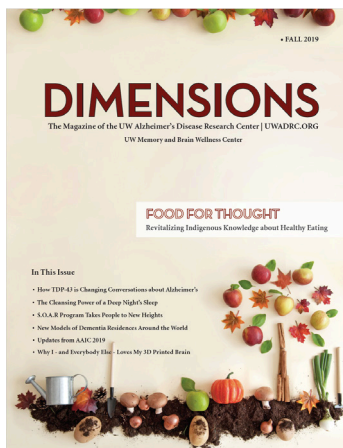
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## Support the Alzheimer's Disease Research Fund

Donations help support patient- and family-centered care, research breakthroughs in Alzheimer's disease and related disorders, and the training of tomorrow's physicians. And by giving — perhaps in gratitude for care, or in memory of a loved one — you can help improve the lives of your friends, your family, and others in your region. If you would like to be our partner in enhancing health and changing lives, please contact the UW Medicine Advancement Office at 206.543.5686.

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## The Power of an Active Lifestyle to Boost Cognitive Resilience – Even for Those at High Genetic Risk

By Genevieve Wanucha

An active lifestyle in mid-life is one of the few known ways to reduce risk of Alzheimer's disease and related dementias, according to major consensus reports such as The Lancet Commission on Dementia. But what about people at risk of developing dementia at a younger age? Now, a new study adds a hopeful twist: A life full of light exercise and hobbies may slow disease progression, even for those who inherited gene mutations that cause frontotemporal dementia (FTD).

“In the scientific field of FTD, there's still a lot of skepticism about whether these types of lifestyle behaviors can really impact the brain,” says Kaitlin Casaletto, PhD, Assistant Professor of Neurology at the UCSF Memory and Aging Center and ADRC collaborator. Dr. Casaletto is the author of the new study in *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*. “To show that perhaps behaviors could be linked to better outcomes for people at such a high biological risk for dementia is really exciting.”

FTD is a spectrum of neurodegenerative diseases that affect behavior, decision-making, language, or motor function, and typically begins between the ages of 45 and 65. It is the most common form of dementia in people under 65, accounting for 5 to 15 percent of dementia cases

overall. Forty percent of cases are linked to several known genetic mutations.

In this high-risk group, doctors see a wide variability in outcomes. Some people live symptom-free for longer than others, while others experience more severe disease – sometimes even members of the same family – suggesting a role of other biological or environmental factors. “We hypothesized that the activities people engage in each day of their lives may contribute to the very different trajectories we see in clinic, including when the disease develops and how it progresses,” says Casaletto. For folks who carry genetic mutations, this idea gives hope that the future isn't set in stone.

The team studied how lifestyle differences impacted the progression of FTD in 105 people with dominant genetic mutations. These people were still asymptomatic or had experienced only mild, early-stage symptoms. The participants came from two large multisite studies, recently combined into the ALLFTD study, led by the UCSF Memory and Aging Center. The UW ADRC is one of the ALLFTD study sites and contributed participant data to this new research on resilience in FTD.

Researchers tracked the progression of participants' disease over time, based on measures collected during annual visits. These include MRI scans to measure the

amount of brain degeneration, tests of thinking and memory, and self-reports of daily cognitive and physical activity, for example, reading, jogging, taking classes, gardening, or cooking. At the same time, their family members completed assessments of how well their loved ones were doing with managing finances, medications, self-care, driving, and so on.

Even after only two to three visits (one to two years into the ongoing study), Casaletto and her team saw significant differences in the speed of progression and severity of FTD symptoms between the most and least mentally and physically active individuals in the study, with active lifestyles showing similar effects across participants. From the family member reports, the researchers found that functional decline was 55 percent slower in the most active 25 percent of participants, compared to the least active 5 percent.

Even among participants with progressive brain atrophy detected in a follow-up MRI scan 1 year later, the most active participants continued to perform twice as well as the least active participants on cognitive tests. These results suggest that engaged lifestyles may help the brain to better withstand effects of FTD, a phenomenon called cognitive resilience.

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“The results suggest that an active, healthy lifestyle can potentially enhance the capabilities of brain tissue, despite the physical change that has happened,” says Dr. Kimiko Domoto-Reilly, Assistant Professor of Neurology at the UW MBWC and ADRC, and ALLFTD UW site Principal Investigator. “This is a good reminder that we can’t just look at a person’s brain scan and jump to conclusions about someone’s symptom progression.”

As a caveat, this study reports correlation, not causation. It wasn’t designed to account for the possibility that some participants have less active lifestyles because early effects of disease are already impacting their ability or motivation to be active. “This nice paper from UCSF focusing on a small group of persons at high genetic risk for frontotemporal dementia didn’t address this concern, so there may be some doubt about whether they were finding a potentially modifiable factor or a consequence of a

person’s developing early manifestations of FTD,” said Dr. Eric Larson, MD, Clinical Professor at the UW School of Public Health/Senior Investigator and Executive Director at Kaiser Permanente WA Health Research Institute. “However, the findings that a physically and mentally active lifestyle might confer resilience makes sense in the light of an abundance of existing evidence from other research.” Dr. Larson authored an influential 2006 study showing that exercise was associated with reduced risk for dementia in a community cohort of adults in the UW Adult Changes in Thought Study.

To better define the benefit of active lifestyles in FTD, the researchers plan to conduct clinical trials that manipulate cognitive and physical activity levels in people living with FTD, or at risk for developing FTD. These studies would involve taking actual measures of activity, with wearable technology, for example.

The results are welcome news to clinicians

who ache to help high-risk patients interested in how to best protect their brain health. “This is a population that needs hope now – not later,” says Dr. Domoto-Reilly. “How do we jump in and help? It’s incredible to have found support for non-pharmacological interventions that are immediately implementable and customizable to what the individual already loves to do.” •

## SOURCES

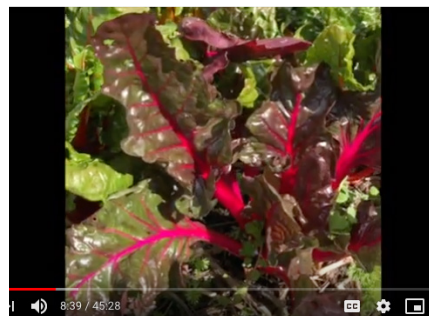
- K.B Casaletto et al. Active lifestyles moderate clinical outcomes in autosomal dominant frontotemporal degeneration. *Alzheimer's & Dementia*, 2020.
- Exercise is associated with reduced risk for incident dementia among persons 65 years of age and older. *Annals of Internal Medicine*, 2006.
- The ALLFTD Study: [allftd.org](http://allftd.org)

Image credit: *ld\_germain, Flickr*

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## The Garden Discovery Walks Go Virtual!



The Memory and Brain Wellness Center and Seattle Parks and Recreation have always been proud to offer the popular Garden Discovery Walks program, a monthly garden tour and horticultural therapy-inspired art craft. While we wait until we can visit gardens again, registered horticulture therapist Laura Rumpf, HTR, a long time co-facilitator of the Garden Discovery Walks, is helping the program remain vibrant and thrive. She has recorded an exploration of Bradner Gardens Park, featuring a creative activity focused on cherry blossoms, tailored for people living with memory loss and care partners.

We are grateful to our sponsor, Family Resource Home Care for their generous support of this program!

Here is the link to the 45-minute video: <https://youtu.be/YO08QHC-uv4>. The tour of the garden is 30 minutes at the beginning. The activity is demonstrated in the last 15 minutes. Enjoy the surprising colors and textures of flowers and vegetables in mid spring.

**If you plan to follow along with the creative project**, here are a list of supplies needed: Sheet of paper for background- printer paper or other quality or color of paper; Pink or white tissue paper or construction paper; cotton balls or pads; Glue or tape; Drawing utensil: any kinds of pen, pencil, marker, crayon; Watercolor paint.

### Read:

Staying Active & Bringing the Outdoors Inside! Resource List: Virtual Tours, Nature Apps, Home-based Exercise, Live Streams: [www.depts.washington.edu/mbwc/content/page-files/Outdoors\\_Inside.pdf](http://www.depts.washington.edu/mbwc/content/page-files/Outdoors_Inside.pdf)

The Importance of Nature in Times of Social Distancing by Dr. Carolyn Parsey, PhD, neuropsychologist: [www.depts.washington.edu/mbwc/news/article/the-importance-of-nature-in-times-of-social-distancing](http://www.depts.washington.edu/mbwc/news/article/the-importance-of-nature-in-times-of-social-distancing)

## "Shoring Up the Foundation"

Some of the Center's clinical and research team members share how they are staying healthy and centered during uncertainty and stress.

### **Thomas Grabowski, MD, Medical Director, Neurologist:**

I've been trying to take a daily walk and keep my eye open for nature photography opportunities - like this little fellow eating the buds from my plum tree:



### **Kris Rhoads, PhD, Neuropsychologist:**

My approach to staying healthy has centered on bolstering my ability to tolerate ambiguity and distress, while doing my best to consolidate strengths and qualities that get you through the long haul - things like grit, perseverance and fortitude. For me, there are a couple things that shore up the pillars of these traits, including:

- A daily gratitude practice - taking stock of at least 10 things for which I'm thankful. This almost always includes the constants of family, friends, colleagues and people in my life as well as daily specifics, the more specific the better. Once a day at least, the more frequent the better.
- Doing what I can to give back and help someone else - Small stuff like holding the door, checking in on someone, a compliment, etc.
- Doing something physical – getting out of the mind and into the body and world.
- Not taking myself too seriously. I try to regularly remind myself that I am but a very small, brief and delightfully insignificant part of the greater whole. This is wonderfully freeing and does not in the least absolve one from committing to any of the above.

In short, I'm shoring up the foundation.



### **Carolyn Parsey, PhD, Neuropsychologist:**

Spring veggies are here and I'm getting inspired by new, healthy recipes in the kitchen. I'll be planning my summer garden and trying to find space for "just one more" container for some June-bearing strawberries.



### **Tuei Chiem, RN, BSN, Registered Nurse:**

I find that meditation helps when I "think too much" or feel anxious. I do 20-minute meditation sessions on my yoga mat, 3-4 times a week, with zen music and eyes closed.

### **Marigrace Becker, MSW, Program Manager of Community Education and Impact:**

I've been using Facebook chat and Zoom video calls to have group interactions with my family. I go for a run or walk most days. And I've made up ways to have socially-distanced-fun with the kids next door – drawing pictures and posting them in our windows, or writing secret messages with a code for the kids to unravel.



### **Michael Schrift, DO, MA, Geriatric Psychiatrist:**

I'm enjoying cooking at home instead of going to restaurants and hiking with my wife on the weekends.

### **Karen Clay, MSW, Social Worker:**

Going outside and making a point to notice the variety of plants coming up and flowers blooming and to listen to the many bird songs.

**Kimiko Domoto-Reilly, MD, Neurologist:**

I open the curtains wide each morning to let in the daylight. I'm also going on walks, exploring new neighborhoods, and trying new recipes.

**Charles Bernick, MD, Clinical Professor, Director of Clinical Trials:**

I am using this isolating time to do more running and sunning, walking with my wife and dog, and getting around to projects that there never seemed time for.

**Mike Persenaire, MD, Neurologist:**

I've been practicing guitar and Vipassana meditation, working out, and reading for work and pleasure. I make sure to get lots of fresh air in parks that aren't crowded and stick to a regular bedtime and meal schedule.

**Elisabeth Lindley, MN, ARNP, Nurse Practitioner:**

I've been gardening, listening to the radio, cooking and baking, making kimchi, staying in touch with friends and family by phone or social media, and playing tennis—staying 6 feet away from opponent, of course.

**Annika Noreen, PhD, PMP, Program Manager:**

I love carefully watching the progression of my plum blossoms on the young trees, and in the coming months hope to watch them mature into fruit for the first time! I also rejoice at every worm, bee, and butterfly in the yard - good soil, active pollinators - life is going on all around us.

**Theresa Kehne, Research Coordinator:**

To stay centered and sane, I have been learning new music on my guitar, going on runs in unexplored corners of town, and planning future backpacking adventures over online platforms like Hangouts and Zoom with my friends. This way, we can stay connected and also have fun trips to look forward to when the wait is over!

**Jessica McDougall, Research Coordinator:**

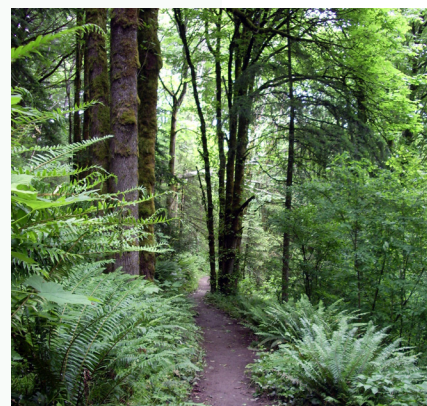
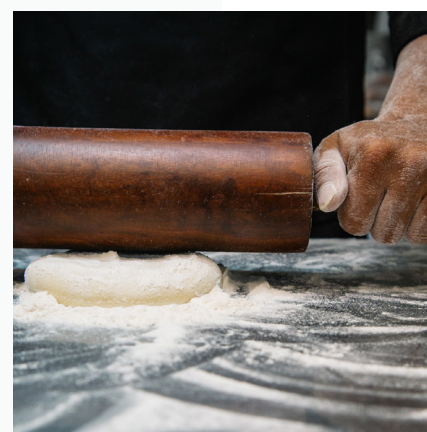
Most days I take a long break outside and walk to a small forest park in my neighborhood where I notice the daily changes in spring growth and watch and listen to all the birds. I've met new neighbors along the way and have been harvesting stinging nettles to try in new recipes for pesto, lasagna and soups.

**Genevieve Wanucha, MS, Science Writer, Communications Team Lead:**

I've been searching outside for flowers, such as violets, daffodils, and cherry blossoms, and bringing samples inside to paint with colored pencils and watercolors. It's a wonderful way to link up creativity, mindfulness, and nature. Plus, it creates a record of the season.

**Franklin Faust, Science Writer, Communications Team Member:**

I've been playing roleplaying games like Dungeons & Dragons with friends over group video chat software! I find that the group problem-solving and team building dynamics are very therapeutic. Physical distancing doesn't mean you can't stay socially connected!



# Home Is Where the Art Is

## Can a Creative Indoor Environment Help Loved Ones Age in Place?

by Cal Dobrzynski

Doris Barlett lived in central Pennsylvania her entire life and in the same purple Victorian-style mother-daughter house on Elm Drive in Watsonstown, PA for nearly 60 years. Her son, Chuck, and his wife Vondelle lived in the ‘daughter’ side of the split home. When Doris was diagnosed with Alzheimer’s disease in 2001, she continued to live in her home, a place where she felt safe, comfortable, and in control. She could sit on the same purple-and-white checkered couch where she watched *Dancing with the Stars* every Monday night, with the decorative electric fire flickering in the background. She could stay in the space where she knew how to use the rotary telephone that hung on the kitchen wall, despite it being 20 years out of date.

As her Alzheimer’s symptoms progressed, Doris confused dates and times. She would write notes to herself so that she could try and remember birthdays and appointments, but nothing seemed to work. Chuck would check on her nearly ten times a day, preparing her meals and making sure that she was taking her medicine at the correct times. Check-ins were more prominent on Mondays, when *Dancing with the Stars* was on, to make sure the television was working properly, as Doris had trouble turning it on and off.

At the time, Watsonstown did not have community facilities for families taking care of a loved one with Alzheimer’s disease. There were no organizations that offered in-home care to relieve Chuck from his duties. And there were few to no social or art programs available in the small town of 2,250 people. So, the television became Doris’s main form of stimulation.

When I turned 12, I started to write letters to Doris, my great grandmother, and Chuck, my great uncle, would send back her responses. We quickly became pen pals. Two years ago, Doris’s daughter, my grandmother, found all of the letters that I had sent, so I decided to find the ones that she had written to me. And while her letters were usually incoherent, her penmanship never faltered and she always drew doodles and drawings in the margins, something I hadn’t thought much about when I was 12.

Doris lived in her home until April 30, 2009. It was at this point that her children decided to place her in a nursing home facility, just for rehabilitation. Doris would ask, ‘how long am I going to be here?’ and my grandmother told her that she would head back to Elm Drive soon, that this was only temporary. But on the thirteenth day in the nursing home facility, Doris passed away.

At her funeral, people were asked to make donations to the American Diabetes Association, because Doris had always told my grandmother that she was too embarrassed to have people find out that she had issues with her memory. She was scared that people she knew her entire life would mock her, make fun of her. There was no mention of her cognitive impairment in her obituary, and there was no talk of it at her funeral.

Now, eleven years later, my great grandmother’s experience with Alzheimer’s disease has had a profound effect on my life and inspires my work as a Master of Design graduate student at the University of Washington. It was during last winter break that I found the letters that my great grandmother had written to me back in 2007 stuffed in a folder in a drawer. Seeing the doodles and her perfect penmanship made me wonder about the creativity that continues to live in people despite having a diagnosis of Alzheimer’s disease, and how can we better enable potential. I think about how the home can become a place conducive to creativity, energy, and activity instead of loneliness or confusion.

During the spring of 2019, I met Marigrace Becker, Program Manager of Community Education and Impact at the UW Memory and Brain Wellness Center, who opened my eyes to the amazing programming and opportunities to work alongside folks who were making huge strides in the world of dementia care in the Seattle area. I was able to partner with Elderwise and the Gathering Place, two Seattle organizations that provide arts programming for people living with dementia. I often thought about people who live in rural areas, just like my great grandmother, Doris, who are unable to partake in such helpful initiatives. Together, we created an interactive installation at the 2019 Seattle Design Festival titled *Looking Forward*. The installation aimed to shift the dialogue surrounding and the stigma against dementia by showcasing artwork and narratives created by local individuals living with dementia. >>>



The goal of the installation was to show the community that by empowering individuals with dementia, we can begin to create a dynamic and inclusive city, where all members can thrive.

Through this installation, I started to notice the amazing conversations that were taking place around dementia. The physical space at the festival made it easier for parents to explain the concept of memory loss to their children and why some family members can't remember certain things, like their name. This installation opened a lot of visitor's eyes to the amazing things people diagnosed with dementia can still create, despite their cognitive differences.

Choosing a topic for my Master's thesis was not difficult. There was, and still is, very little information on how the arts and small changes to the built environment could help stimulate those living with Alzheimer's disease. I started wondering about how art-making in domestic settings could help family caregivers (spouses, siblings, children, etc.) communicate better with their loved ones living with Alzheimer's disease. How can the visual and built environment affect the mood and motivation of a person living with Alzheimer's? Can this have an affect on a person's creativity?

For our first quarter show, held at the Jacob Lawrence Gallery at UW, I wanted to show visitors the difficulties that family caregivers and the person living with Alzheimer's go through on a daily basis while living in their home. In order to do this, I personified objects within the space. For instance, the red plate on the table says 'When Doris was diagnosed with Alzheimer's, they bought me, a bright red plate. My color helps her spatially differentiate me from the table and her food when Chuck is helping her eat'. These visual personifications were based on a 2004 study, conducted by Boston University Vision & Cognition Lab of the Center for Clinical Biopsychology researchers, who found that when people who were diagnosed with Alzheimer's disease ate off of a red plate, they were likely to eat up to 25% more food. These kinds of small but mighty visual alterations are amazing non-pharmacological approaches that can make a huge difference in the daily life of both the caregiver and their loved one living with Alzheimer's.



*'When Doris was diagnosed with Alzheimer's, they bought me, a bright red plate. My color helps her spatially differentiate me from the table and her food when Chuck is helping her eat'.*

For the past few months, I have also been conducting materials studies, exploring how different mediums and textures help individuals living with any stage of Alzheimer's express themselves. In February, I had the opportunity to visit a nursing home facility in South Seattle, where I brought a variety of materials, including clay, pipe cleaners, pastels, cut paper, watercolors, and crayons, to their memory unit. What I found was that the participants did not necessarily care what materials they were using, they simply wanted to 'make' and interact with one another. I also found the following insights to be helpful:

**Limit art-making time to 30-45 minutes**

**Plan the activity for a certain time of day (perhaps in the morning before lunch, or in between lunch and dinner)**

**Provide participants with a choice of materials**

**Set up the art-making space prior to the activity**

**Provide a prompt**

**Engage the senses (perhaps turn on music, brew some coffee, open up the window)**

The main goal of my thesis is to conduct art-making in the home, and I am hopeful that some of these easy-to-implement insights can empower family caregivers to engage with their loved ones through creativity on a regular basis. In order to do this, I proposed an individualized art-making kit that caregivers and their loved one with Alzheimer's can interact with. By providing the tools they need, I am hopeful that family caregivers can form new ways to communicate with their loved ones living with Alzheimer's. As I create my case study kit, I am drawing on what I have found out about how people with Alzheimer's disease may perceive colors, textures and sensory information. For example, age-related thickening of the lens of the eye makes it difficult to differentiate blues and purples. I am opting to use colors in the warmer range, such as reds, oranges, and yellows. I'm opting for natural, calming patterns instead of busy patterns. These design principles can be utilized both within the art-making kit and in the built environment. •

*My thesis is still a work in progress and will culminate in a public presentation on June 5th, 2020 at the Husky Union Building and a final exhibition at the Henry Art Gallery from May 23rd - June 21st, 2020. (With news changing by the day, the presentation might be held online.) If you have any insights, feedback, or questions, please email me at [cdoby@uw.edu](mailto:cdoby@uw.edu). For more information on this project, please see [caldoby.com](http://caldoby.com).*

**Images** - Page 14, top: Doris Bartlett / Doris, Chuck, and Caroline / Cal and Doris; Page 15: Cal Dobrzynski's show at the Jacob Lawrence Gallery



# The Memory Hub

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

This year, the UW Memory and Brain Wellness Center (MBWC) is proud to launch 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 the Frye Art Museum, welcoming visitors year-round to explore what it means to live well with dementia.

### A PLACE FOR DEMENTIA-FRIENDLY COMMUNITY

Over the past five years, the UW MBWC has offered a variety of community programs and events that provide the opportunity to learn, grow, connect, be active, and engage strengths of people living with dementia and their care partners. But until now, we haven’t had a warm and welcoming place outside the hospital to house these programs.

#### The Memory Hub is that place.

The Memory Hub will be a dynamic community center offering education, support and wellness programs for people with memory loss and their families. It will house current MBWC programs and programs offered by partner organizations – from support groups to caregiver workshops, from creative arts and technology classes to horticulture therapy experiences. In addition, it will include a rotating gallery of art made by persons with memory loss, a memory loss resource center/library, an arts-based adult day program, and a social worker to assist with navigating community resources. Outside, an inviting green space will feature a botanical garden uniquely designed for people with memory loss.

### A PLACE FOR COLLABORATION AND INNOVATION

We are proud to be a part of a growing network of individuals and organizations committed to building dementia-friendly communities. Partnerships on the local and state level – such as the Momentia movement and the Dementia Action Collaborative – have led to significant gains such as the recent launch of the Dementia Friends public awareness campaign here in Washington. We know we can accomplish more together. But until now, there hasn’t been a physical place for these collaborators to gather, share ideas, and accelerate innovation.

#### The Memory Hub is that place.

The Memory Hub will house up to five mission-aligned organizations on-site, as well as informal co-working space. Not only will this make it easier for people with memory loss and their loved ones to connect with multiple helpful organizations simultaneously, it will also facilitate collaboration. The Memory Hub will offer networking, resource-sharing, and professional development events, as well as community forums and other platforms for surfacing innovative ideas.

### A PLACE FOR STATEWIDE IMPACT

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

#### The Memory Hub is that place.

The Memory Hub will offer training opportunities like workshops and conferences, as well as the chance to observe model programs and learn how to implement them. In alignment with the Washington State Dementia Action Collaborative, it will house state-of-the-art video conferencing technology that will support and equip a statewide network of dementia practitioners. Associated staff will be available to provide guidance on launching strength-based programs and dementia-friendly community initiatives across the state.

Building community, accelerating collaboration, driving statewide impact. Welcome to the Memory Hub: A Place for Dementia-Friendly Community, Collaboration, and Impact!

### WHAT’S NEXT FOR THE MEMORY HUB

The Memory Hub is undergoing renovation this Summer and will open later in the Fall. Stay tuned to learn more about our on-site collaborator organizations and the date for a special community launch celebration!

- Stay tuned for updates: [www.depts.washington.edu/mbwc/resources/memory-hub](http://www.depts.washington.edu/mbwc/resources/memory-hub)
- For more information, contact:

Program Manager for Community Education & Impact, Marigrace Becker: 206-744-2017, mbecker1@uw.edu. >>>



## A Memory Garden is Growing



Inspired by the continuing interest in nature and garden experiences in our community, the Memory and Brain Wellness Center is creating a memory garden for people living with dementia. This garden will be located at the Memory Hub, located beside the Frye Art Museum. The botanical garden is uniquely designed to enhance the lives of people living with dementia, as well as provide a relaxing, restorative space for all. The garden will serve as a spot for drop-in gardening, relaxation, and nature-based activities, such as horticultural therapy.

The garden design process is ongoing and incorporates feedback from community members living with memory loss and care partners, as well as lessons learned from the Garden Discovery Walks program of the MBWC/Seattle Parks and Recreation and a visit to our friends at the Portland Memory Garden.

### TEAM

- Genevieve Wanucha, MS, Memory Hub Green Space Project Lead, MBWC
- Laura Rumpf, HTR, Healing Garden Consultant
- Margaret (Peach) Jack, MA, CC, GRS, HTS, Landscape Designer and Therapeutic Horticulturalist
- Marigrace Becker, MSW, Program Manager of Community Education and Impact, MBWC

### INTERESTED?

- The memory garden team is interested in hearing from individuals, home gardeners, businesses, or organizations who may be able to donate certain perennial plants and herbs, compost, or mulch. Please email [gwanucha@uw.edu](mailto:gwanucha@uw.edu).
- To sign up for occasional updates about new and ongoing volunteer gardening and garden maintenance opportunities, please email: [gwanucha@uw.edu](mailto:gwanucha@uw.edu).
- Financial donations will help support the ongoing development of the healing garden. For donation inquiries, please contact [mbecker1@uw.edu](mailto:mbecker1@uw.edu)



Preliminary Garden Design Concept #1. Margaret (Peach) Jack, Landscape Designer



One of two focus groups held at the UW MBWC in February 2020



Preliminary Garden Design Concept #2. Margaret (Peach) Jack, Landscape Designer

## ADRC RESEARCH TIPS for Potential Study Participants: Q & A

*My name is Theresa Kehne, I'm a Research Coordinator at the University of Washington, Alzheimer's Disease Research Center (UW ADRC) in Seattle. I spend a lot of time talking with patients and their care partners or family members about potential research opportunities when they come to the Memory and Brain Wellness Center for clinic visits. Here are some common questions I receive during visits:*



**Q** *What's the difference between the ADRC and the Memory and Brain Wellness Center?*

**A** The Memory and Brain Wellness Center clinic helps patients get a proper diagnosis and aids with clinical care, memory loss education, and support resources, while the Alzheimer's Disease Research Center (ADRC) does research. Getting involved in research at our ADRC is completely voluntary and won't impact a patient's medical treatment. In addition to our ADRC, there are 32 other ADRCs across the U.S., all designated by the National Institutes of Health to conduct similar research about brain health and dementia.

**Q** *How is research information about me protected?*

**A** At the UW ADRC, all researchers must comply with the federal law HIPAA (Health Insurance Portability and Accountability Act), which protects people's private health information. There is also a UW authority called the Institutional Review Board (IRB) whose job is to review all research projects at the UW and make sure that they are safe for and fair to participants. Finally, all potential participants have unlimited time to read and ask questions about a study, prior to agreeing to join the study, and then at any point during the study. This process is also known as "informed consent." Once you are enrolled in a study you can choose to withdraw at any time, without penalty.

**Q** *Can I see my results from a study procedure or test?*

**A** It is up to the investigator conducting the study to decide if any test results will be shared with participants. Examples of potential study results that may be shared are information from brain imaging (e.g., MRI or PET scans), blood draws, lumbar punctures, or written tests to assess cognitive function. Usually this matter is outlined in the informed consent documents. Every study is different and study staff can let you know which test results, if any, will be made available to you.

**Q** *What is a lumbar puncture?*

**A** A lumbar puncture is a procedure used in certain clinical and research settings during which a doctor collects a sample of cerebrospinal fluid from a person's lower back. This fluid is used clinically to help diagnose a patient. During research, cerebrospinal fluid permits direct measurement of Alzheimer's disease proteins, and may also offer investigators the opportunity to develop novel tests. To learn more about lumbar punctures and what to expect if you plan to have one, check out our "Lumbar Punctures – FAQs and Myths" page on the UW ADRC website: [www.depts.washington.edu/mbwc/adrc/page/lumbar-punctures-faqs-and-myths](http://www.depts.washington.edu/mbwc/adrc/page/lumbar-punctures-faqs-and-myths)

**Q** *What do Research Coordinators do?*

**A** Research Coordinators are responsible for the day-to-day tasks involved in a research study. Research Coordinators enroll participants, conduct study tests and lab work, maintain detailed records of research activities, work closely with investigators, and help to make sure that studies run smoothly. Research Coordinators are experts on specific research study protocols and receive extensive training in ethics, good clinical practice, and biomedical research involving human participants. >>>

**Q** *What kinds of research projects/studies are going on currently that are looking for participants?*

**A** The UW ADRC offers research opportunities that are both observational and interventional in nature. Observational research aims to learn about brain disease and healthy aging through studying people with methods like neurologic examination, brain imaging, and cognitive tests, while interventional research evaluates the safety and effectiveness of different potential treatments and interventions (e.g., clinical trials, or investigational treatment studies).

The UW ADRC would like to express our resounding gratitude to those of you who choose to become involved in research. Your participation is a gift to scientific discovery and medical innovation. Thank you for all that you do! •



## Technology for Early Dementia Diagnosis

We are studying wearable technologies that may be useful to help diagnose **Alzheimer's disease** and **dementia with Lewy bodies**.

You may qualify for this study if you meet these requirements:

- Have a diagnosis of Alzheimer's disease or probable dementia with Lewy bodies
- Have a friend, family member, or caretaker who is able and willing to answer questions about you
- Have at least 8 years of education

Volunteers who complete the study will receive up to \$250 in appreciation for their time and participation.

**VA**



U.S. Department of Veterans Affairs  
Veterans Health Administration  
Geriatric Research, Education, and Clinical Centers

VA Puget Sound IRB Approved  
10/16/2019

For more information, please call the  
Research Study Coordinator at **(206) 277-1379**.

The Principal Investigator of this study is  
Dr. Debby Tsuang at S-182 GRECC, VA Puget Sound,  
1660 S. Columbian Way,  
Seattle, WA 98108

VA Puget Sound R&D Approved 11/07/19

FOR ALL ENROLLING STUDIES, PLEASE VISIT: [www.depts.washington.edu/mbwc/adrc/page/clinical-trials](http://www.depts.washington.edu/mbwc/adrc/page/clinical-trials)

# Sweeping Aside the Clouds: The Wisdom behind Indigenizing Evidence-Based Health Programs for Elders

By Ka`imi Sinclair, PhD, MPH and Genevieve Wanucha, MS

**B**ecky Bendixen is a Tribal Program Specialist at the Northwest Regional Council in Bellingham, Washington. The NWRC's Tribal Outreach Program serves the Lummi, Nooksack, Samish, Sauk-Suiattle, Swinomish, Upper Skagit, and Tulalip Tribal communities and has successfully linked Native Elders with services and information on aging.

Eight years ago, Bendixen co-created Wisdom Warriors, an ongoing, incentive driven program that provides Native Elders the education, support and tools to make healthy choices resulting in lifestyles that promote self-care, active lifestyles, and longevity. She received the 2017 National Impact Award from the National Indian Health Board for her contributions to enrich and improve American Indian and Alaska Native health at a national level.

In this interview, she generously shares the story driving her passion to improve the health and wellbeing of Elders and of Native communities more broadly. It is one of heartbreak, healing, and the power of connecting to Unangam traditional culture and dance.



Would you tell us about your cultural background and the roots of your current passions to improve health interventions for Native communities?

I was raised in King Cove, Alaska, a village of about 800 locals and about 300 transient members of canning crews that came in for salmon and crab fishing seasons. We were really isolated. My mother and her three sisters originally lived on St. Paul Island, the largest of the Pribilof Islands of Alaska. They spoke their language, Unangam Tunuu, until they were six years old, and then they were prohibited from speaking their language and were forced to learn and speak Russian and English. My mother would tell stories of the non-Native colonizers beating her when she went to school because she spoke only her language. Obviously that trauma was ingrained in our Elders, and they wanted to protect us. So, they didn't teach us our language, our dances, or our spirituality.

I think it was around 1990, when I was in my 30s, a gentleman called Ethan Petticrew came from far down the Aleutian Island chain, to King Cove to teach our traditional Unangam dance. We were just fascinated that this dance was a part of who we are. But we didn't know the dance. We had heard stories of it, but we had never learned it ourselves. And I had never seen Unangam dancers before then. My heart was full as I watched Ethan, the dancer leader, speak in their Native language with my Mom, who translated it into English for us. And it was the most beautiful thing I'd ever seen because my niece and all of our children were out on the dance floor, doing our traditional dances, singing our traditional songs, and using our language. There were so many tears in the audience. It was like a part of us was coming back to us that had been taken away for almost two centuries.

When I started getting involved in my culture, it felt like someone had broken away this shell that had been put around me, and I was finally allowed to become a part of my land. I became a part of the earth that I had grown up on. I was finally allowed to be a part of it, because of my culture. And the more I practiced my culture, the stronger I became. It makes me feel like I am finally a whole human being. I am relevant now. I don't feel like I did before. It's so hard to put into words. >>>

### Can you describe Unangam dance?

Our dances are very vigorous. There's a lot of spinning and jumping. What is very unique about our style of dance is that we use our hands, we use our feet, and we use our voices to tell the story connected to our culture. If you watch our dancers' hands, you can see the motion of the waves in the ocean.

And the wind would be spinning you in circles, because up in Alaska, we have hurricanes all the time. You would see the men paddling kayaks. You would see each movement, and each movement would tell a story. When we are dancing, our ancestors are out there dancing with us.

### What brought you to Washington and started you on your path to Wisdom Warriors and public advocacy work with Native communities?

I moved to Washington State after 41 years at home. My people, the Pribilof, took part in a canoe journey from St. Paul Island to Port Angeles, Washington. I will never forget when our team of canoes arrived and landed in front of 1,000 tribal people. The tradition is to sing our songs for all. And so, we carried our uluxtax (what you would call a kayak) inside and got out in the middle of the dance floor. None of us knew our traditional songs in our language. We all knew just bits and pieces of some songs. So, we sang a Russian Orthodox Church song. It was beautiful, but it wasn't our song. And it just broke my heart. It was at that moment that I decided that we needed Unangam Tunuu traditions and culture in Washington State.

That's when I formed a 501(c)(3) nonprofit called Northwest Unangam Culture. Over the years, we would hold what we call 'culture camps,' where we would bring traditional teachers from Alaska and hold intensive 10-day, 10-hours-a-day culture camps, focusing on dance, history, culture and language. By the end of those 10 days, almost all the participants would have learned their language and history, learned a few songs, and created their dance regalia—ornate, flowing dress garments made by hand just as our ancestors would have done from furs that are indigenous to the islands that we come from. We continued that for many, many, many years, until I lost my parents. When you're grieving, you can't do spiritual work, dancing, and celebrating. I'm still healing from the loss of my parents. So, we haven't danced in six years. We're just now talking about getting ourselves back together.

### Do you find any of those activities to be especially helpful or healthy for Elders?

I really don't see many Elders of any tribe dancing that much. I think it has a lot to do with the historical trauma from having our culture taken from us. But Elders love to see the young people dance. They definitely love to help the children with their language if they still have it. My approach to healing tribal Elders is getting them involved in making traditional crafts. It's a time when they can gather, they can do something that they were taught to do as a child, and they can tell stories. And that's where you get the treasures. The whole room goes silent when an elder speaks about the past. It's incredible.



Becky Bendixen

### How did the Wisdom Warriors health intervention program start?

While working with tribal communities at the Northwest Regional Council, my supervisor Shelly Zylstra and I found that there are many evidence-based programs to improve health, but they don't work effectively in indigenous communities. That is because the people who develop these programs come from outside our communities; they're non-Native. They do not look or talk like us, and they don't know our history. Our local tribal elders who experience chronic conditions, such as diabetes, high blood pressure, and heart disease, wanted a program to help them manage their conditions and one that reflected their culture and values. We decided the best solution was to develop our own program. We created Wisdom Warriors, a culturally adapted version of the 6-week Chronic Disease Self-Management (CDSMP) curriculum that researchers at Stanford University developed in 1996.

>>>



This Unangax dance troupe of people of the Aleutian Islands is called Sngagim Axasniikangin, translated as Dancers of the Dream — "The dream to bring our traditional dances back." Credit: Becky Bendixen

The Wisdom Warriors program content is the same as the original program, but we infused it with Native traditions and values, such as making medicine bags, powwow dancing, carving, fishing and more. Wisdom Warriors also honors tribal sovereignty by encouraging tribal nations to tailor the program to fit their own customs and health needs.

Wisdom Warriors is now in its 8th year and is an ongoing program in many communities that continue to offer other culturally relevant programs to the Wisdom Warrior "cohorts" that have been established across the US.

Elders wanted a program that would continue on after six weeks, so we developed a plan for each class after they completed the initial Wisdom Warriors chronic disease self-management classes. Every month, participants start with their action plan, which is at the very core of chronic disease self-management. From there, they go into traditional crafts, traditional foods and preparation, and some health activity, such as seated Tai Chi, seated yoga, or just plain stretching; anything that's healthy for the body. They practice every day and they have monthly meetings to celebrate each other's success in reaching a variety of health milestones, which are recognized with decorative beads worn on the medicine pouches.

We now want to work with folks down in Seattle to reach urban Elders.

### **What is your process of adapting chronic disease management programs for Native Elders?**

The first program we indigenized was the CDSMP. We have also done pain management and diabetes management. Last month,

we added a Tai Chi intervention from the Tai Chi Institute of America.

To create an adapted version of a program, we do the six-week training workshop in the evidence-based program, and we then teach it our way (i.e., indigenize it). We never lose the key lessons of the programs, but we take the same lesson and make it more relevant to the tribes and their cultures. The people we teach then take the program to their communities. Each tribe designs their Wisdom Warrior program to match their elders' needs and their elders' culture. Our goal is to give Native people the tools and techniques to indigenize any evidence-based program to promote health.

### **Can you describe what it means to Indigenize a health intervention?**

Let's take Tai Chi as an example. I love both standing and seated Tai Chi, but I don't connect with how they've named the movement forms. So, we renamed the forms, using an object that we could all relate to. Here, it was the moon. I made a story about carrying the moon in a basket, to pair with each movement. For the movement called 'Open and Close', you are opening your hands and then bringing them back together. Instead, I say, "I want you to reach forward and gather the moon. And then I want you to lift the moon up and out, and then share her with your cousins." And you do the hands waving in the clouds, sweeping aside the clouds, bringing the moon closer, and putting your moon into the basket. Each movement tells a story of what you are doing with the moon.

>>>

You are using the moon to bless yourself and the people in your friendship. And the elders absolutely love it.

Each tribal community can tailor their own story. The Pima might choose the blooming cactus; other tribes might choose the eagle.

**How does Wisdom Warriors benefit the health of elders? For example, we've learned that Dr. Keawe Kaholokula and his team in the Department of Native Hawaiian Health, University of Hawai'i, recently completed a hula intervention for Native Hawaiians with high blood pressure and the program significantly reduced systolic blood pressure.**

One of the aims, the health outcome aims, is brain health and the prevention of dementia. We find that Elders who are in this program have increased their physical activity by so many, many, many hours. And they're part of our tagline: Living stronger, Living longer. We have one tribe that has actually reduced Elder visits to the clinic and hospital by 40%. And we see decreases in depression, because at least once a month, they're getting together with the Wisdom Warrior family. They're preparing food together. They're exercising together. They're growing crops together. They're feeding young people with indigenous crops. It's kind of wonderful what's happening.

**Has your personal family experience with memory loss influenced your work?**

As I watched my mom's mental decline, they first told me it was

because of her diabetes and then vascular dementia. At that point, I thought so many of our Elders have diabetes, there has to be a way for us to fight that battle. I wanted to make it so that no other family would have to go through what I went through. I wanted people to have accessible education about diabetes and other health issues that would prevent them from ever having half the problems that we have. But I find in tribal communities that we're only just beginning to talk about dementia itself. It's still kind of taboo. The more we talk about it, the more Elders will realize that they're not "crazy." It's dementia. So, we use Wisdom Warriors to get those messages across to Elders, and then when they go out in the community, they're also sharing good, hopeful messages. •

*This interview was conducted by Ka`imi Sinclair, PhD, MPH (Associate Professor and Co-Director, Partnerships for Native Health/Institute for Research and Education to Advance Community Health, College of Nursing, Washington State University) and Genevieve Wanucha, MS, Science Writer, UW ADRC/Memory and Brain Wellness Center*

#### MORE INFORMATION

- 2009 Unangax dance performance of 'Creation': [www.youtube.com/watch?v=v7VTaLfrbk](http://www.youtube.com/watch?v=v7VTaLfrbk)
- Wisdom Warriors, Northwest Regional Council: Information and contact list: <https://tinyurl.com/y5yus2q5>



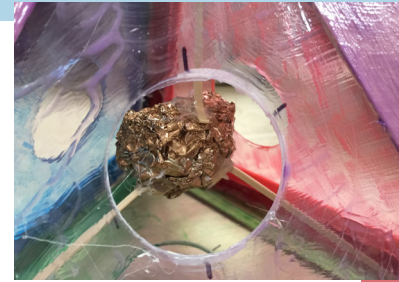
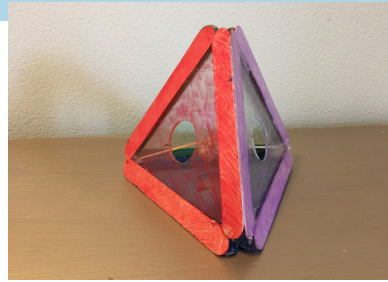
#### Explore UW ADRC Indigenous Aging Resources!

- **UW ADRC Indigenous Aging Webpage:** [www.depts.washington.edu/mbwc/adrc/page/indigenous-aging-resources](http://www.depts.washington.edu/mbwc/adrc/page/indigenous-aging-resources)
- **Tribal Outreach Video** - A Project of the UW Alzheimer's Disease Research Center and Partnerships for Native Health from Sky Bear Media. Watch at [www.vimeo.com/314071595](http://www.vimeo.com/314071595)
- **ADRC Toward Precision Medicine Seminar: 'Native Peoples and the All of Us Research Program: Inclusion, Collaboration, Governance, and Benefit'**, with Dr. Spero Manson, PhD, Distinguished Professor, University of Colorado Denver. The video is now available on our Native AD Research page: [www.depts.washington.edu/mbwc/adrc/page/indigenous-aging-research-education](http://www.depts.washington.edu/mbwc/adrc/page/indigenous-aging-research-education)
- **Food For Thought: Revitalizing Indigenous Knowledge about Healthy Eating:** An ADRC Indigenous Aging Brain Health Series Interview with Valerie Segrest, a member of the Muckleshoot Nation and leading voice in tribal food sovereignty, about her approach to traditional foods and how to harness the power of food to improve health, longevity, and spirit. <https://tinyurl.com/y9tnca37>

## Wicked Diseases, Advocacy, and Gifts, Oh My!

### My Journey from Disease into Advocacy powered by P.R.I.S.M and P.U.S.H

Community member Kevin Kvarda has created a sculpture to represent the hope and optimism behind his advocacy for people living with dementia and caregivers, medical professionals, researchers, and support associations.



**Hello Friends!** My name is Kevin Kvarda or you can call me “K-Squared.” Since June 2019, I’ve had new friends in my life--a diagnosis of Alzheimer’s and Primary Progressive Aphasia: “PPA”. I’ve not necessarily been one to stand up on the public stage, but my diseases have pulled me out and given me a voice ... a positive VOICE and HOPE.

I have a GREAT Caregiver team: My wife Norma, 4 kids (Riley, Andrew, Quinlan, and Jordan), extended family in other states, and many friends from past work teams, and my men's spiritual groups.

I sometimes think of my new experience in the terms of “The Wizard of Oz” movie, in that we have a Scarecrow that needs a brain (and I have a brain that is different due to the diseases), a Tin Man who needs a heart (and I have a huge heart because of family, friends, and awesome physicians, etc.), a Lion that needs courage (and I have strong courage from family, spiritual Men’s groups, and taking one day at a time). And even though there is the Wicked Witch of The West in my story, we have many organizations that are working around the clock trying to find the CURE! Remember what happened to the Wicked Witch of The West in the end!



And now, it's time to go on down the "yellow brick road" and give you a glimpse of my early days and the diseases/medical issues up to now (young to now): **Tonsils and Adenoids Removed** — **Glasses** — **Cholesteatoma surgeries (4 times from 5 to 19) in right inner ear** — **Breathing-treatments in the ER, usually at night** — **Allergies** — **Orthodontics (Head Gear)** — **Scoliosis** — **Pituitary gland tumors (4 surgeries, 1 Gamma-Knife** — **Thyroid issues (Hypo, Hyper...varies)** — **AFIB episodes (2 times)** — **Lumbar puncture** — **Alzheimer’s** — **PPA** — **Dementia** — **What's Next?** — **HOW ABOUT A CURE FOR ALZ, PPA, and Dementia!! -We need Wizards!**

Overall, I have embraced my diagnosis, which is causing my Dementia, Aphasia, and Disability. YES, I really did say that! Crazy huh...but it's true. They are unique and go with me every day. Since I found them, they have given me opportunities to make others laugh, get mad, and cry too.

I believe that NOTHING comes by “accident”. There is ALWAYS a reason! I also believe that all of us have a higher power that guides us. It doesn't matter what your faith (or not) is. Mine is my Roman Catholic Christian faith. What is your higher power? Embrace it, cling to it, use it to help others and yourself! I believe that we ALL have our Guardian ANGELS. I'm convinced that those angels do amazing feats EVERY day. I'm deeply thankful! BELIEVE!!

#### My Mission:

As an Advocate “in training” for the cure for Alzheimer’s, PPA, and Dementia, I co-create a world where these diseases are eradicated by 2025 by working with local agencies in Olympia, WA and Washington D.C. I educate myself via my medical professionals, local events, MANY support groups, family, and friends.

#### P.R.I.S.M: Patients, Researchers, iHumanity, Support Associations, and Medical Professionals

As a Systems Engineer, Product Manager, Robotics Coach, and Project Manager by trade, I’ve always been interested in how things fit together. I drew on my passion for engineering and visual thinking to communicate my big idea: A prism with 4 facets. This prism is no ordinary prism. It has its own acronym: **P.R.I.S.M**. All sides support each other, to increase strength and hope. The golden ball you see hanging inside the prism symbolizes humanity. ALL 4 facets MUST be running and “In Mission” to ENSURE that Humanity is in BALANCE. We ALL have a part to keep the BALANCE! We all need to keep pushing up the hill in our own ways. In other words: P.U.S.H: Power, Unity, yields Solidarity and Hope. Here are my wishes to help you work towards your own Missions. If you have a personal/professional Mission and would like to share, I would be grateful. As they say...**“Iron sharpens Iron”**. >>>



## P.R.I.S.M.:

Patients and Caregivers, Researchers, iHumanity, Support Associations, and Medical Professionals

### BLUE: Patients & Caregivers:



I wish you **PATIENCE** when working with the doctors, nurses, aides, etc.

I wish for you to **EMBRACE LIFE** one day at a time.

I wish you **TRUST** between **BOTH** Patients and Caregivers.

### RED: Medical Professionals



I wish you **IMMENSE EMPATHY** everyday!

I wish you **ADEQUATE TIME** for your patients, families, studies, and you.

I wish you **COMPASSION** and **STRENGTH** for the journey with every patient.

### PURPLE: Support Associations

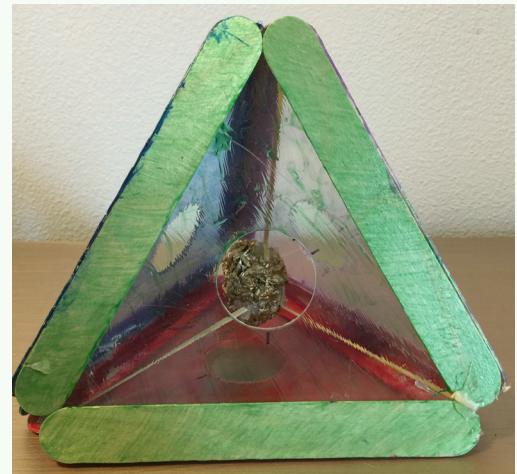


I wish you a **TENACIOUS HEART** when working with legislators at the State and National levels for funding for the cure for **ALZ**.

I wish for you to continue **SERVICE LEADERSHIP** (especially at community events).

I wish for you to continue **EXPANDING TO MORE CITIES** so that new folks can get the information.

### GREEN: Researchers



I wish you an **HONEST** heart when working on a cure and enough time to get it right.

I wish you never-ending **CURIOSITY**.

I wish you a **SHARP INTELLIGENCE** when communicating to others.

## Advocacy Day 2020 in Olympia, WA

On February 18, 2020, I traveled to Olympia to act as an Advocate for the WA State Chapter of the Alzheimer's Association. It was Advocacy Day, when anyone can participate and urge public officials to support additional resources for Alzheimer's disease. I decided to share my personal story.

I had nerves that morning—after all, I haven't been one to get up and give speeches all of the time! But, I felt I needed to right then. I just took the opportunity and gave it what I could. And, it came out good. I talked about how I turned 180 degrees after my diagnosis and made a not-great thing into a great thing, through advocacy. In all, I visited five different legislative offices. It was pretty cool because at every meeting, I heard things like, "Wow, I never heard a story like yours before."

What we do is really critical to keeping the balance for patients and caregivers, researchers, medical professionals, and support associations. Think of these groups as the 4 sides of the P.R.I.S.M. If one side isn't running at 100%, then all of the other 3 sides will have to pick up the load. -Kevin Kvarda



Anyone can BECOME AN ADVOCATE through the Alzheimer's Association. Advocates are invited to engage public officials and policymakers in a variety of ways, from trip to Congress, to emails and Facebook posts, urging their support for critical Alzheimer's legislation and policy changes. <https://tinyurl.com/88z5jv7>

**Recommended Apps and Virtual Resources >>>**

# Recommended Apps!

When Kevin Kvarda presented his story at the MBWC's Primary Progressive Aphasia Education Day 2019, he shared some Smart Phone apps, including brain games, cognitive exercises, and education modules, that he has found beneficial for some time. Here is a list!

- > **The Alzheimer's Association Science Hub** (*Free*) is an app that provides the latest news, information and expert views about Alzheimer's and dementia research. The Alzheimer's Association shares the latest research news and perspectives from scientists and other credible sources. Website: <https://www.alz.org/help-support/resources/the-alzheimer-s-association-science-hub>
- > **Brain Yoga** (*Free*) Eleven puzzle games train your memory, vocabulary, numeracy, spatial ability and pattern matching. Website: <https://apps.apple.com/us/app/brain-yoga-brain-training-game/id660526568>
- > **Constant Therapy**: is a science-based mobile solution for highly personalized, continuous exercises for people with aphasia, dementia and other speech, language, and cognitive disorders caused by stroke or traumatic brain injuries. Constant Therapy was designed by scientists at Boston University and provides tools for self-help and tools for patients to work with their clinicians. Website: <https://thelearningcorp.com/constant-therapy/>
- > **The National Aphasia Association** has compiled a list of apps for people living with Aphasia. Website: <https://www.aphasia.org/aphasia-resources/aphasia-apps/>
- > **Alzheimer's Universe** Created by Weill Cornell Medicine & New York Presbyterian, AlzU is an educational tool to assist on the journey to protect brain health. Website: <https://www.alzu.org/what/>
- > **3D Brain** Use your touch screen to rotate and zoom around 29 interactive structures. Discover how each brain region functions, what happens when it is injured, and how it is involved in mental illness. Each detailed structure comes with information on functions, disorders, brain damage, case studies, and links to modern research. Created by Vivid Apps and AXS Biomedical Animation Studio for the Cold Spring Harbor Laboratory DNA Learning Center. 3D Brain was produced for the Genes to Cognition (G2C) Online website funded by the Dana Foundation and Hewlett Foundation. Website: <https://dnalc.cshl.edu/resources/products/3d-brain-app.html>
- > **PopWords** A simple and fun word finding game Website: <https://apps.apple.com/us/app/popwords/id472853634>
- > **A Walk through Dementia** is a Google Cardboard app designed to put the player in the shoes of someone living with dementia. Website: <https://www.awalkthroughdementia.org/>

## ACKNOWLEDGMENTS

- My family of 5, my mother, father, brother, and many relatives in different states.
- All of my doctors and nurses along the way (Everett Clinic, Virginia Mason Hospital, and Providence Everett, and, of course, the UW Memory and Brain Wellness Center and UW Radiology teams).
- All the workers at the wahealthplanfinder (medical insurance).
- Marigrace Becker, Dr. Kimiko Domoto-Reilly, Genevieve Wanucha, Brad Rolf, and James DeLappe (UW Medicine) and Megan Caldwell (UW Speech & Hearing Sciences)
- Hazel Borden, Katya Strohl, and Peter Newbould (Alzheimer's Association WA State Chapter).
- My 3 spiritual men's groups.
- The staffers I talked to at the Capitol in Olympia at Advocacy Day 2020.

## LEARN MORE

- Contact Kevin Kvarda: [kevin.kvarda@gmail.com](mailto:kevin.kvarda@gmail.com)
- 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-uTsrrx-i0>.
- Enjoy Kevin Kvarda's Powerpoint presentation from PPA Education Day, 'From Disease to Advocacy.' Download: <https://tinyurl.com/y8fdox7q>



“The struggle you're in today is developing the STRENGTH you need for tomorrow. Peace Out" - K-Squared

**\*NEW\* Virtual Support, Education & Engagement in the time of COVID-19**



**In-person MBWC Community Programs and Events are on hold until further notice, but we are adapting. Our clinic team has taken some programs virtual and invented a variety of virtual support and education options, tailored toward the experience of living with memory loss or caregiving in this extra challenging time. Participate online or by phone, with a free application called “Zoom.”**

>> **To SIGN UP for these programs, visit:**  
<https://tinyurl.com/yb8ujv4m>

**COFFEE CHAT FOR PERSONS WITH MEMORY LOSS/ DEMENTIA (ZOOM)**

**Tuesday, May 5, 10 - 11 a.m.** Theme: Solidarity

Make a cup of coffee or tea, and come together for an informal social time with others living with memory loss or dementia. Share how you're coping in the midst of COVID-19, or offer an encouraging story or bit of humor to lift each other's spirits. Facilitated by program manager Marigrace Becker. Space is limited; sign up by the day before.

**CAREGIVER FORUMS (ZOOM)**

Come together with other family caregivers to discuss caring for a loved one in this time of COVID-19. Make meaningful connections, offer mutual support, and discover strategies that work for others. Facilitated by clinic social worker Karen Clay and program manager Marigrace Becker. Space is limited to 20 participants; sign up by the day before. Join for just one session, or multiple.

**Monday, May 4, 10 a.m:** Supporting a Loved One at a Memory Care Facility (General Themes)

**Monday, May 11, 10 a.m.:** Supporting a Loved One at Home (General Themes)

**Monday, May 18, 10 am.m:** Supporting a Loved One in any Setting (General Themes)

**HEALTHY BRAIN AGING SEMINARS (ZOOM)**

The MBWC offers public talks on brain health at Seattle area Era Living communities throughout the year. RSVP to Sonja.martin@eraliving.com at the Gardens at Town Square, or call the community directly at (425) 688-1900.

**Wednesday, April 29, 2 p.m.** Memory Loss: What's Normal, What's Not? with neuropsychologist Carolyn Parsey, PhD.

**Thursday, May 7, 2 p.m.** Diet, Exercise and Brain Health with geriatrician Dr. Lee Burnside, MD.

**COMMUNITY WELLNESS TALKS (ZOOM)**

Join us for a brief presentation and Q&A on various topics related to “living well” in the midst of the COVID-19 outbreak. These talks are for people with memory loss, family caregivers, and the general public, and feature MBWC providers. Participate online or by phone, with “Zoom.” Join for just one session, or multiple.

**\*Wednesday, April 29, 10 a.m.** Enjoying the Arts from Home with geriatrician Lee Burnside, MD. [\*Note: this session is at 10 a.m. rather than 1 p.m.]

**Friday, May 1, 1 - 1:45 p.m.** Virtual Nature for the Soul with neuropsychologist Carolyn Parsey, PhD.

**Wednesday, May 6, 1 - 1:45 p.m.** Food for Thought: Brain Healthy-Meals" with geriatrician Angela Hanson, MD.

**\*EXTRA!** View the Power Point from previous session “Just Relax’ – Far More Helpful Strategies for Stress Management” with neuropsychologist Kristoffer Rhoads, PhD:  
<https://tinyurl.com/ya7qufu7>

**GARDEN DISCOVERY WALKS (VIDEO)**

A virtual adaptation of our popular nature program will explore local gardens and demonstrate creative art activities, tailored for people living with memory loss and care partners. *See Page 11 to learn about this program!*

**Take part now:**

**A Virtual Walk through Bradner Gardens and Art Project:**  
<https://youtu.be/YO08QHC-uv4>

**Seward Park Forest Walk: May 2020 Virtual Garden Discovery Walks (Part 1 of 2):** <https://youtu.be/90wjXo3pbrU>

**Making a Bird Nesting Bundle from a Pine Cone: May 2020 Virtual Garden Discovery Walk at Seward Park (Part 2 of 2):**  
<https://youtu.be/pgB4klxz1qc>

Remember to check the MBWC website for new or future offerings: <http://depts.washington.edu/mbwc>

Inspired by the MBWC's Posterior Cortical Atrophy Day!



## PCA FACEBOOK GROUPS

- **\*NEW\* The Northwest PCA Connection & Resources Facebook Group** was launched in April by local PCA caregivers Maureen Devlin and Dave Richards. This private group is a place to share local resources, support, camaraderie, and maybe even a little humor, among those in the Pacific Northwest who are affected by PCA. It is open to people with PCA, family members and caregivers: <https://tinyurl.com/NorthwestPCA>
- **PCA Vision** has a PCA Support page on Facebook and a monthly lecture series and a national support group through a video platform called ZOOM. Learn more: <https://pca-vision.org/>

## WEB RESOURCES & SERIES

**Rare Dementia Support:** <http://www.raredementiasupport.org/pca>

- Home design tips
- Facts about perception and hallucinations

**AbilityNet:** <https://abilitynet.org.uk/>

- List of resources and tips for accessing technology

**Royal National Institute of Blind People (RNIB):** <https://www.rnib.org.uk/practical-help/technology/resource-hub>

- List of technologies available for people with visual impairment

**PCA Video Lecture Series** with host Jamie Talan, featuring guest lecturers:  
<https://www.youtube.com/channel/UCCg51pmMC9eXvkufYekPMw/videos>

## LITERATURE

“**Unraveling Posterior Cortical Atrophy: Not Seeing Things That Are There**” by Jamie Talan:  
<https://www.gbhi.org/news-1/unraveling-posterior-cortical-atrophy-not-seeing-things-that-are-there>

**AlzForum:** <https://www.alzforum.org>

- Posts about news on Alzheimer’s research and related dementias

## RESEARCH OPPORTUNITIES

- University of Washington Alzheimer’s Disease Research Center: <http://depts.washington.edu/mbwc/adrc/page/clinical-trials>
- University of San Francisco Memory and Aging Center: <https://memory.ucsf.edu/dementia/posterior-cortical-atrophy>

## ORGANIZATIONS

Alzheimer’s Association, WA State Chapter  
206.363.5500 <https://www.alz.org/alzwa>

Lighthouse for the Blind  
206.322.4200 <https://lhblind.org>

Washington Talking Book and Braille Libraries  
206.615.0400 <https://wtbbl.org/>

Vision Matters  
888.281.1492 <https://www.visionmatters.net/>

PCA-vision  
516.330.6498 <https://pca-vision.org/>

# Aging with Pride: IDEA



*Dr. Karen Fredriksen Goldsen, Professor at the UW School of Social Work and Director of UW Healthy Generations Hartford Center of Excellence, is an internationally recognized gerontologist and scholar in addressing health inequities of at-risk elders and their caregivers. She and her research team are creating the first ever dementia intervention tailored to address the unique needs of LGBTQ older adults living with memory loss and their caregivers: Aging with Pride's IDEA (Innovations in Dementia Empowerment and Action) Study, currently enrolling at [ageIDEA.org](http://ageIDEA.org).*

## **What is the origin of your research on health outcomes of LGBTQ elders?**

Our research team has been investigating the health disparities of historically disadvantaged populations, especially populations that have limited access to services, for 25 years. We identified LGBTQ older adults as a population in high need. For the last decade, our team has been conducting Aging with Pride: National Health, Aging, and Sexuality/Gender Study (NHAS), the first National Institutes of Health (NIH) funded longitudinal national project designed to better understand the aging, health, and well-being of LGBTQ midlife and older adults and their families and caregivers. The study follows 2,450 LGBTQ adults ages 50 to 102 and tracks their health and well-being over time. We partner with 17 community agencies across every US census division.

Before the Aging with Pride study, there were no large health studies of LGBTQ older adults and their caregivers. Information about disparities in health and cognitive impairment in this population just wasn't available.

It was difficult to get such a study funded when we first started. LGBTQ elders are a largely invisible population, around which there was a lack of awareness of health disparities. Funding agencies thought that this population of seniors wouldn't participate in the project because they were too hidden and that we couldn't reach them. But actually, people did participate in our project, and have stayed engaged. We have a 94% retention rate in this longitudinal study.

## **What do you know about health and dementia risk factors for the LGBTQ community of older adults?**

LGBTQ older adults have many strengths. They have built communities, friendships, and families, and they are resilient in many ways. But at the same time, they are less likely to seek

services in part because of their experiences and history of discrimination. We found that lesbian, gay, and bisexual older adults have disparities in accessing medical care, and higher prevalence of chronic health conditions and cognitive impairment and memory loss, compared to heterosexuals of similar age. It's very concerning to see these elevated rates of cognitive impairment.

Once we identified higher rates of cognitive impairment, we then wanted to understand the unique risk and protective factors in this community of elders. We found there are many risk factors that are associated with dementia, or Alzheimer's disease, in this community. For example, they are more likely to have HIV/AIDS, some subgroups are more likely to smoke, and they show higher rates of depression and psychological distress. These are just some of the factors likely associated with higher rates of cognitive impairment.

## **How are you putting these lessons into action, with the Innovations in Dementia Empowerment and Action (IDEA) Study?**

Because I'm an expert in the health of disadvantaged elders and their caregivers, I wanted to partner with an expert in Alzheimer's disease and dementia. I contacted Linda Teri, PhD, one of the world's leading experts in non-pharmacological treatments in dementia care. She is now Professor Emerita at the UW School of Nursing and past Director of the Northwest Roybal Center for Translational Research on Aging. We put our heads together. We quickly became inspired by a protocol called Reducing Disability in Alzheimer's Disease (RDAD), developed by Dr. Teri. This validated protocol has worked to reduce stress and increase physical activity in people with dementia and their care partners.

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We decided to utilize RDAD as the foundation and then designed and integrated specific components to address the unique needs of the LGBTQ population and evaluate its effectiveness in a clinical trial which we named the Innovations in Dementia Empowerment and Action (IDEA) Study. The intervention is being offered in Seattle, San Francisco and Los Angeles.

IDEA is a free six-week cognitive behavioral intervention program where a care partner and a person living with dementia (called a dyad) are matched up with a coach. One person in the dyad needs to identify as LGBTQ - it can be either the caregiver or the person living with dementia (or both). We train coaches in this cognitive behavioral intervention in three areas: problem solving, communication, and low impact exercise. The coaches help both the caregiver and the person experiencing memory loss develop strategies to solve problems that may arise, in nine one-hour sessions. We compensate people for the time that they spend on five phone assessments during the program. For each assessment the dyad successfully completes, they are given \$25, for a total of \$125 for the five assessments.

There has never been an intervention designed around the unique and distinct needs of LGBTQ older adults living with memory loss and their caregivers. A culturally relevant intervention uses appropriate language and addresses their history of discrimination. In the IDEA study, we want to ensure that this community can access support resources that they may not have been able to in the past. We are also thinking about what kinds of services need to be available for this community. We want to know if this program, adapted for LGBTQ adults, improves the quality of life for people with dementia and their care partners.

#### **Future hopes for study?**

Moving forward, I'm hoping we can extend our translational research to ensure that all LGBTQ elders and their caregivers have access to a culturally appropriate intervention. Ultimately, we want to provide this intervention across the nation.

Importantly, we have found that about half of the people who want to enroll in this study don't have a caregiver. We have now received funds from NIH to develop a pilot project focusing on people who don't have a caregiver to accompany them in a research study like this. All of this work gives us very important insights for other at-risk and underserved communities and how Alzheimer's disease and dementia impact communities at large.

#### **What can the UW Alzheimer's Disease Research Center and the Memory and Brain Wellness Center clinic do to help?**

I think it is really important to get the word out that this intervention program is available and addresses the distinct needs of LGBTQ older adults who are experiencing dementia and LGBTQ caregivers of those with dementia. LGBTQ older adults are much more likely than the general population to have friends who provide their care instead of legal family members. These friends might not think about themselves as a caregiver or that they have enough time to engage in this project. Just one person in the dyad needs to identify as LGBTQ. It is really important to let people in this situation know that they are eligible to participate. We want to reach people as early as possible, so they get the help they need. Right now, there is still room in the program for new participants. •

## **Aging with Pride: IDEA**

### **Are you or someone you know experiencing memory loss or difficulty remembering?**

Check out this free six-week program to:

Reduce stress

Increase physical activity

Help solve problems related to memory loss

This program is for the LGBTQ community, whether you are the person experiencing memory loss or their care partner.

### **The pair will be compensated \$125 for their time.**

To learn more and to check eligibility:

**1-888-655-6646 | [ageIDEA@uw.edu](mailto:ageIDEA@uw.edu) | [ageIDEA.org](http://ageIDEA.org)**

This program is offered by the University of Washington and community partners in Seattle, San Francisco, and Los Angeles

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