

• SPRING/SUMMER 2019

DIMENSIONS

The Magazine of the UW Alzheimer's Disease Research Center | UWADRC.ORG

UW Memory and Brain Wellness Center

TALK ABOUT A REVOLUTION

THE FUTURE OF VOICE BIOMARKERS IN THE NEUROLOGY CLINIC



- Busting Myths about Alzheimer's Treatments and Diets
- Closing the Gaps in Dementia Care for Asian Americans
- Building Bridges with the African American Alzheimer's Community
- A Life in Review: Legacy Creation Through Palliative Care

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 2019!

In these pages, you will learn about a quest to detect and help diagnose Parkinson's and Alzheimer's diseases—using only voice samples, the unique experiences of dementia within the Asian American community, and how palliative care helps people create lasting legacies. Our clinicians take the opportunity to bust some myths about Alzheimer's disease treatments and special fads. Don't miss the article 'Building Bridges with the African American Alzheimer's Community', as well as new poems, artwork, and upcoming events! Most importantly, we hope you hear an encouraging message about Alzheimer's disease and related conditions: persons 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 and support of our work. The Ellison Foundation, the Richard M. and Maude Ferry Charitable Foundation, Paul V. Martinis Estate, the Anderson Foundation, and the Sky Valley Whirlwinds and other generous groups, make it possible for us to move faster in research and reach out further into the community than ever before. We're all in with you. Happy reading!



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FEATURED PUBLICATIONS

Neurology

Bilingualism in Primary Progressive Aphasia: A Retrospective Study on Clinical and Language Characteristics. A. Costa et al. *Alzheimer Disorders & Associated Disorders*, January 2019 // Kimiko Domoto-Reilly

Primary progressive aphasia, or PPA, is a neurodegenerative disorder that impairs language abilities over time, such as speaking and word finding. The international team, including the ADRC's Dr. Kimiko Domoto-Reilly, MD, recognized an interesting opportunity to study the manifestation of language decline in PPA patients who were bilingual, or spoke two or more languages. They asked about the influence of speaking multiple languages on the progression of diseases that specifically damage the language networks of the brain. Can bilingualism confer resilience to the brain's language networks or delay symptom onset? Does an English speaker's native language hold up better than their Spanish as primary progressive aphasia progresses? What language should an individual's speech therapy focus on? In general, there is conflicting evidence on whether being bilingual has a protective effect on neurodegenerative diseases, such as Alzheimer's disease.

The researchers studied 33 patients with diagnoses of one of the three types of primary progressive aphasia: the nonfluent, semantic, and logopenic variants. They found that the group as a whole showed the same level of impairment in both first and second languages, supporting the idea that neurodegeneration has a blanket effect on language. However, each variant of primary progressive aphasia showed subtle differences of impairment between the two languages. These results reveal that researchers need to better assess language in different variants of PPA, including other influential factors such as the person's age of becoming fluent, proficiency, and which language was dominant in their life. In an increasingly multilingual world, the researchers anticipate an increasing need for a multilingual approach to research and care management in neurodegenerative diseases, in order to improve the reliability of diagnosis and access to tailored speech therapies.

Precision Medicine Approaches

Genetic data and cognitively defined late-onset Alzheimer's disease subgroups. S. Mukherjee et al. *Molecular Psychiatry*, December 2018 // Shubhabrata Mukherjee, Emily Trittschuh, Madeline Wessels, Juliana Bauman, Mackenzie Moore, Seo-Eun Choi, Joanne Rich, Diana K.N Loudon, R. Elizabeth Sanders, Thomas J. Grabowski, Thomas Bird, Susan McCurry, C. Dirk Keene, Eric B. Larson, ACT Study researchers, Paul K. Crane

ADRC researchers recently made a leap forward in the aim to classify patients with Alzheimer's disease into subtypes, an approach that may open the door for personalized treatments. In collaboration with many other institutions, the researchers put 4,050 people with late-onset Alzheimer's disease into groups based on their most prominent type of cognitive symptoms at the time of diagnosis. These included memory, executive functioning, language, visuospatial functioning. Then, they dug into everyone's genetics. The team searched the participants' genetic data to find biological differences across these cognitive groups. Taking this novel approach, they found 33 single nucleotide polymorphisms (SNPs) – specific locations throughout the genome – where the genetic association was very strong for one of the subgroups. These genetic-cognitive relationships were stronger than the strongest effects found by the much larger International Genomics of Alzheimer's Project Consortium in which Alzheimer's disease was treated as a single homogeneous condition. The study also found a strong relationship between a particular variant of the APOE gene and risk for the memory loss subgroup. The APOE4 allele is a risk factor for developing Alzheimer's disease for people with European ancestry. It now appears to influence which cognitive subtype of Alzheimer's a person is likely to have, if they develop symptoms.

This study is an important step toward improving insight into the types of variability that clinicians see in the initial cognitive symptoms of late onset Alzheimer's and the genetic factors that seem to make certain circuits in the brain vulnerable or resilient to Alzheimer's pathology. Additionally, the study sets forth a new platform for the discovery of genetic variants linked to distinct clinical types of Alzheimer's disease and the design of targeted treatments.

Genetic Risk

Alternative splicing in a presenilin 2 variant associated with Alzheimer disease. J. Braggin et al. *Annals of Clinical and Translational Neurology*, March 2019 // Jacquelyn E. Braggin, Stephanie A. Bucks, Meredith M. Course, Carole L. Smith, Bryce Sopher, Leah Osnis, Kiel D. Shuey, Kimiko Domoto-Reilly, Christina Caso, Chizuru Kinoshita, Kathryn P. Scherpelz, Thomas J. Grabowski, Gwenn A. Garden, Debby Tsuang, Caitlin Latimer, Luis F. Gonzalez Cuyar, C. Dirk Keene, Richard S. Morrison, Kristoffer Rhoads, Ellen M. Wijsman, Michael O. Dorschner, Jessica E. Young, Paul N. Valdmanis, Thomas D. Bird, Suman Jayadev

A collaboration of ADRC researchers has led to a discovery about the genetic cause of a rare form of early-onset Alzheimer's disease, with surprising implications for the general aging population as well. They focused on individuals in two families harboring a 'frameshift' mutation within the presenilin 2 gene (PSEN2), previously identified for the first time by ADRC researchers in 2010. To understand a frameshift, think of the affected section of DNA as a series of linked train cars, except that several train cars get disconnected by accident. It's too short to be sent to its destination. However, it was unclear to the researchers why that frameshift causes severe disease. Drawing on a multidisciplinary array of ADRC resources, they studied genetic data and postmortem brain tissue, and they used patient cells to measure molecular hallmarks of Alzheimer's disease.

The team found that the PSEN2 gene of these patients indeed generates abnormal instructions for making protein, as expected. However, working with the UW Valdmanis lab, the team uncovered the presence of an additional set of flawed instructions that are not unique to this mutation, but that also appear in other cases of Alzheimer's disease and in normal aging brains. This finding opens the door to the possibility that age-related changes in PSEN2 expression may be involved in Alzheimer's risk in the general population. It is only when the bad instructions are decoded in the genomes of people with the frameshift in the PSEN2 gene, the researchers report, that a perfect storm of toxic proteins could result and eventually lead to early-onset Alzheimer's. Their study highlights the importance of understanding the link between PSEN2 and Alzheimer's disease.

Vascular Brain Health

Vascular Risk Factors and Findings on Brain MRI of Elderly Adult American Indians: The Strong Heart Study. D. Shibata et al. *Neuroepidemiology*, February 2019 // Dean Shibata, Astrid Suchy-Dicey, Cara Carty, Tara Madhyastha, T Ali, L Best, Thomas J. Grabowski, WT Longstreth, Dedra Buchwald

Stroke and cardiovascular disease are known to put people at risk for vascular brain disease, Alzheimer's disease, and cognitive decline. While cardiovascular disease is prevalent in American Indians, the risk factors for the impacts on the brain have not been well-studied in this population. The Strong Heart Study, started in 1988 by funding from the National Heart, Lung, and Blood Institute, is the most extensive examination of cardiovascular disease in more than 4,500 American Indians from 13 tribes across three geographic regions of the U.S. Surviving members of the study cohort have participated in many examinations ever since. In this iteration of the study, conducted by the ADRC Satellite Core, some of the Strong Heart Study participants returned for tests related to brain health. The researchers analyzed MRI brain scans of 789 elderly American Indian participants. The study's findings offer more evidence of the significant role of diabetes and high blood pressure in age-related brain damage, as seen in other studied populations. The results underscore the importance of better diagnosis, monitoring, and preventive measures to reduce vascular brain injury in American Indians.

*Only UW-affiliated researchers are listed

Talk About a Revolution

The Future of Voice Biomarkers in the Neurology Clinic

By Genevieve Wanucha

Ten years ago, Jim Schwoebel got a memorable phone call from his mother. She was crying. His brother had been hospitalized after a psychotic break at the age of twenty. Looking back, there had been warning signs: his brother had gone to his primary care physician eleven times complaining of headaches and unclear thoughts. No psychiatric specialist was able to flag his true problem. During that time, Schwoebel took to exploring his collection of eight hundred voicemails from his brother, saved up over the years. As a biomedical engineer and future CEO of NeuroLex Laboratories, Schwoebel wondered if this lengthy verbal record might hold any clues to the speaker's developing schizophrenia. Could there have been a way to catch this condition in one of those eleven clinic visits, from just subtle changes in his voice?

In fact, researchers were just about to find the answer. Starting in 2007, a team from Columbia University and IBM recruited a group of 34 adolescents at a high risk of psychosis and followed them over three years. Five of the people experienced a psychotic episode. Early in the study, the researchers had recorded voice samples from the participants. They analyzed all the sound clips using voice analysis technology, designed to detect the changes in word usage known to emerge in early psychosis. In 2015, the team reported that they could predict which people developed psychosis using only voice with 100% accuracy. Although based on a small sample size, this result far outperformed pen and pencil interviews. This use of voice as a biomarker of disease detection is exactly the kind of tool that could help people like Schwoebel's brother.

A wealth of information about health is encoded in our speech. "Personally, I'm fascinated by voice because it is such a complex task," says UW Medicine's Dr. Reza Hosseini Ghomi, MD, Director of the UW DigiPsych Lab and clinician in the UW Memory and Brain Wellness Center. "Think about how much precision and coordination of muscles and brain regions are involved to produce voice, and various diseases can subtly or acutely affect one's voice and use of language." Early on, emerging disorders may make your voice wobble so mildly that it's not detectable to the human ear. In Parkinson's disease, speech changes include loss of volume, speaking in short rushes, sounding more monotone. Different changes come about during different stages of illness. In developing schizophrenia, words in

sentences become less related to each other; while in Alzheimer's disease, there's long pauses between words, trouble finding words, and use of more pronouns, such as "it," "that," "them," instead of specific nouns and names.

Now, researchers are applying machine learning-based voice recognition technology, such as that developed for Amazon's voice home-assistant, Alexa, to identify voice patterns that are specific to different neurological diseases. And, as with Alexa, people can give voice samples from the comfort of their home. The biotech companies are working to bring to market technology to monitor a patient's health in the clinic or remotely, using smartphone apps or other wearables, with samples of voice. The hope is to use voice data to create non-invasive, inexpensive ways to track changes in symptoms and response to medication, tools called voice biomarkers. What could be simpler than telling an app what you had for breakfast?



Reza Hosseini Ghomi, MD

There is no FDA-approved digital voice biomarker technology currently on the market for clinical purposes, mostly because the field is so new and needs more data. "The field of digital biomarkers is still very fragmented because there are no standards for voice recording or an organizing force," says Dr. Hosseini Ghomi, who is also Chief Medical Officer at NeuroLex Laboratories, working alongside Jim Schwoebel to create voice biomarker technology. "There isn't a national digital biomarker association like there is an Alzheimer's Association, for example, so we need to bring researchers and industry stakeholders together." In a sign of the field's momentum, its very first academic journal, *Digital Biomarkers* of Karger Journal, launched in 2017 to provide a dedicated home for all digital biomarker work. Voice is one form of digital biomarker under investigation, along with finger tapping speed, sleep movements, and walking. Digital biomarker technology, in general, provides clinicians with new avenues to capture symptoms and functional changes in



everyday life. “So often our patients describe symptoms that we do not directly observe in the clinic,” says Dr. Carolyn Parsey, PhD, a neuropsychologist at the UW Memory and Brain Wellness Center. “Real-time data capture, such as through wearable sensors and home-related technologies, collect this data so we can understand what goes on in a typical day. Voice analysis is just one more way that we can capture changes, perhaps before they are noticeable enough to come into the clinic. This means earlier diagnosis, earlier intervention, and better outcomes for patients and caregivers alike.”

For clinicians, voice biomarkers could help solve intractable issues in the care and management of neurological disorders, which are hard to address in a 30-minute clinic appointment. The first goal is improved disease management at home. “I think voice biomarkers have the potential to offer something revolutionary in terms of accessibility and level of improvement for the patient,” says Dr. Hosseini Ghomi. “Voice biomarkers are non-invasive, affordable, and can be used at home.” As a clinician treating patients from the 5 WWAMI states in the northwest, he desperately needs a way to monitor his patients in places like rural Montana, who may not be able to travel to the specialty clinic without hardship. Voice biomarkers could help him modify and customize treatment plans, adjust doses of medication, and recommend injury prevention interventions, all from hundreds of miles away.

At the DigiPsych Lab and NeuroLex Laboratories, Dr. Hosseini Ghomi has been working to develop machine learning models that can translate voice data into a diagnostic tool for neurological diseases, so far, focused in Parkinson’s disease. He currently uses voice samples from a mobile observational study conducted by Sage Bionetworks. The study, started in 2015 and still going, is conducted purely through an iPhone app, mPower, which collects health, motion, and voice data on users with and without Parkinson’s disease. People can download the app and consent for the research. Prompted by text message every day, participants complete activities such as cognitive games, finger tapping, walking exercises, and saying ‘ahhh’. The

mPower study data, consisting of survey responses and mobile sensor measurements, is available for any researcher to use and analyze in studies.

Recently, Dr. Hosseini Ghomi and his team used 65,000 voice samples from about 6,000 people in the mPower study. These were 10-second files of people saying ‘ahhhh’. After removing background noise, the team passed the raw audio through two algorithms to extract the frequencies and acoustic features—

terms familiar to musicians, such as pitch, jitter, shimmer, prosody, loudness, and harmonics. They then fed the audio into their own machine learning models, which are tools to extract meaningful patterns out of massive amounts of busy, raw data.

The team was able to tell between people in the Parkinson’s disease group from the control group, 85% of the time. Their models performed better than the 74% average accuracy of clinical diagnosis

from non-specialist doctors and the 80% average accuracy of movement disorder specialists. “So that’s exactly what we’re trying to get—A dynamic, frequency-based voice biomarker for Parkinson’s disease,” says Dr. Hosseini Ghomi. Because the models performed so accurately with such short, simple audio clips, he believes that even denser data sets with spoken words could provide a superior voice biomarker. The findings were published in the IEEE Xplore Digital Library and presented at the 2018 IEEE Signal Processing in Medicine and Biology Symposium. The group has recently submitted work demonstrating the ability to detect differences in disease severity and even depression symptoms in patients with Parkinson’s disease using only voice.

Dr. Hosseini Ghomi ultimately wants to create FDA-approved voice biomarkers that are truly specific to a disease process—meaning that they can reliably tell the difference between early Parkinson’s, Alzheimer’s, ALS, and frontotemporal degeneration, and help confirm diagnoses. First, researchers need to deeply understand how the vocal changes in these disorders depart from healthy people’s voices. >>

“I think voice biomarkers have the potential to offer something revolutionary in terms of accessibility and level of improvement for the patient.”

To begin, they need a lot more voice samples. A whole lot more. “As a field, we have to get together and pool our data,” says Dr. Hosseini Ghomi. “We also need a uniform standard of collecting voice samples.” Currently, the field’s projects use different file types, recorders, microphones, and quality levels. Going further, he advocates for a national effort that builds off of the existing biomarker collection and use for research. “We need a national voice sample repository.” For example, NIH Alzheimer’s Disease Research Centers could collect voice samples from participants in the longitudinal cohorts, in addition to the brain scans, blood, and spinal fluid.

For all of the simplicity and ease of voice biomarker technology, the field faces complicated hurdles, such as the lack of a national data resource and some privacy concerns. Beyond clips of people saying ‘ahhhh,’ voice samples from commercial technology are impossible to completely de-identify (protect a person’s identity from being connected to their information). Not all patients will want to give voice samples that may contain personal information or let apps have access to their daily activities, however the mPower study has shown a high rate of participant consent for researchers to use their data collected on the Parkinson’s disease smartphone app. “These are signs that our patients and people around the country stand together to help find solutions for neurodegenerative diseases,” says Dr. Hosseini Ghomi.

For now, Dr. Hosseini Ghomi and his fellow clinicians of the UW Memory and Brain Wellness Center hope that research institutions will collaborate with industry to create a national database of voice samples—the terabyte version of those eight hundred voicemails from Jim Schwoebel’s brother. At least, they could sound it out. •

Genevieve Wanucha, MS, is a science writer and leader of the communications team of the UW Memory and Brain Wellness Center/ Alzheimer’s Disease Research Center. She facilitates the Garden Discovery Walks, a nature engagement program for people living with memory loss, co-sponsored by the MBWC and Seattle Parks and Recreation.

ADRC OUTREACH SPOTLIGHT

The ADRC Outreach Recruitment & Education Core team invites everyone to watch a new short film on Alzheimer’s disease, research, and dementia prevention for our Indigenous neighbors in rural and urban areas. The effort is a collaboration between the UW ADRC and Partnerships for Native Health at Washington State University. Sky Bear Media, an Olympia-based Native American-owned company, created the film.

Visit: <https://vimeo.com/314071595>



At the UW Alzheimer’s Disease Research Center/MBWC, we are invested in an effort to reach out to Native American, Alaska Native, and Indigenous communities in the Pacific Northwest, in order to provide information to local clinics and resources to people struggling with memory loss. We hope to improve the wellbeing of people living with a form of dementia, and caregivers, as well as provide opportunities for people of diverse backgrounds to participate in a research study.

For more information about this project, please read our article on this film: <http://depts.washington.edu/mbwc/news/article/a-film-about-alzheimers-disease-for-native-americans>

Awards for Ambitious New Ideas

The 2019-2020 ADRC Pilot Projects



Douglas Barthold, PhD, Research Assistant Professor, Comparative Health Outcomes, Policy, and Economics (CHOICE) Institute, UW Department of Pharmacy

Type II diabetes is a known risk factor for Alzheimer's disease, and insulin resistance is common in both type II diabetes and Alzheimer's disease. Certain medications, including metformin, have been linked with improved Alzheimer's-related neuropathology in mice and human cell studies. However, no studies have examined the relationship between specific oral medications for diabetes and Alzheimer's pathology in human brains. To fill this gap, Dr. Barthold's team in the UW Department of Pharmacy will collaborate with the ADRC to understand the biological mechanisms that could connect widely used type II diabetes medications to dementia diagnosis. They will use neuropathological tissue samples from the ADRC brain bank, which includes brain autopsies from participants in the Adult Changes in Thought Study of Kaiser Permanente Washington. Ultimately, the researchers hope to provide a basis of evidence to support the repurposing of existing medications for the prevention and treatment of Alzheimer's disease and related causes of dementia.



Erik S. Carlson, MD, PhD, Assistant Professor, UW Psychiatry and Behavioral Sciences

The brain's cerebellum plays an important role in coordinating circuits involved in emotional, cognitive, and motor functions. This area shows hallmarks of Alzheimer's disease neuropathology in cases of early onset and severe forms of the disease, and it may be an important player in the very beginning of symptoms. The pilot award will allow Dr. Carlson's lab to take their research in a new direction, moving from their basic neuroscience work in mice into the application of neuropathology and brain imaging data. Specifically, this study will use tissue samples from the ADRC brain bank to study Alzheimer's-related molecular changes in the cerebellum. The team will then examine brain imaging data from the UW Integrated Brain Imaging Center to determine whether the cerebellum's connections with other brain regions are impaired in people living with mild cognitive impairment or dementia due to Alzheimer's disease. The aim is to identify key changes in the cerebellum that may provide novel treatment targets for Alzheimer's disease.

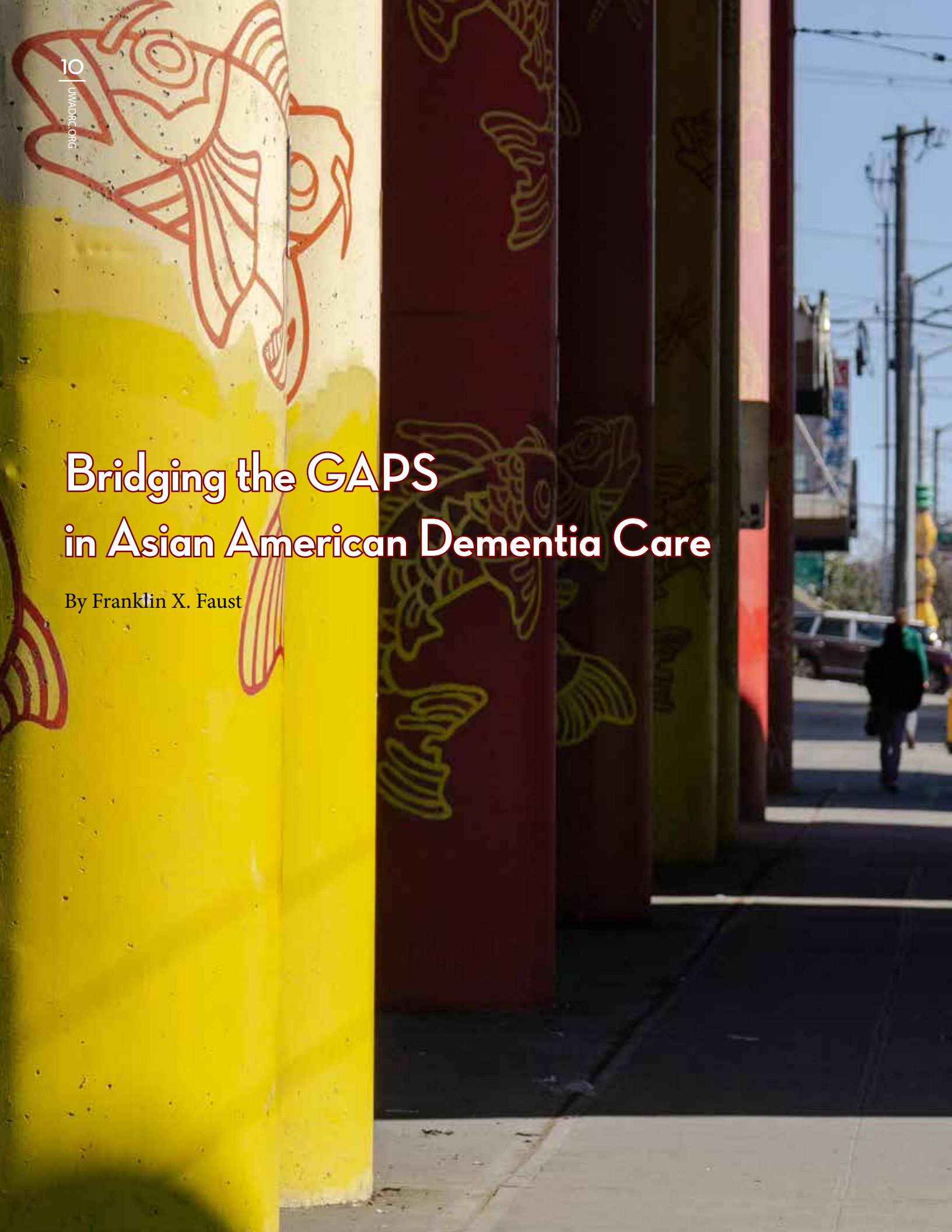


Judit Marsillach, PhD, Acting Assistant Professor of Medicine, UW Division of Medical Genetics

It is now possible to diagnose Alzheimer's disease in living people by using new forms of PET scanning or spinal taps; however, these methods are too expensive or invasive for largescale use outside of research studies or difficult clinical cases. A blood biomarker would offer a low cost, non-invasive option for identifying early signs of Alzheimer's disease. Dr. Marsillach will use this pilot project to study paraoxonase-1, an antioxidant enzyme found in lipoproteins (proteins that carries fat) in the blood and spinal fluid, and may show changes in the development of Alzheimer's disease. Her study will leverage blood and spinal fluid samples from ADRC research participants with and without Alzheimer's disease. She will evaluate whether measures of this antioxidant enzyme can function as a diagnostic blood biomarker for early detection of Alzheimer's disease, to ultimately improve diagnosis and monitoring for affected individuals.

Bridging the GAPS in Asian American Dementia Care

By Franklin X. Faust





A set of photographs depict the cherished memories of Anna Dang, an elderly woman of Asian American heritage. One by one, the photographic memories start to fade to black, and Trang Tu, the woman's daughter and full-time caregiver, opens up about her mother's dementia. This is a scene from *GAPS*, a documentary by Seattle filmmaker Peter Trinh. *GAPS* tells the story of one family's experience with Alzheimer's disease and sheds light on the unique challenges facing Asian American communities in accessing dementia care.

"My goal was to create a documentary that highlights the stigmas, lack of awareness, imbalance of the medical system, and the heavy burden that comes with medical issues that are seen with Asians that are not as apparent in other ethnicities," says Trinh. "Ultimately, this film aims to raise awareness on these cultural issues."

Trinh's goals are in line with those of the Healthy Brain Research Network's Coordinating Center (UW HBRN) at the University of Washington. Under the leadership of Dr. Basia Belza, PhD, UW Professor of Nursing at the de Tornyay Center for Healthy Aging, the center recently produced the *Asian American and Pacific Islander Dementia Action Guide for Service Providers*. The action guide explains how cultural factors pose unique problems that influence dementia outcomes in Asian American communities, presents research findings on effective, culturally appropriate messaging, and offers outreach recommendations and resources to help achieve inclusion of Asian Americans in dementia care services. By reaching out with their new guide and working with both international and mainstream clinics, they aim to be a force for change and address the barriers to care affecting Seattle's vibrant Asian American communities.

One of the cultural barriers highlighted both in *GAPS* and

UW HBRN's action guide is the stigma surrounding dementia. Nikki Eller, MPH, Research Investigator at the Washington State Department of Health, worked on the action guide and has researched the implications of this stigma. Most cultures have some level of stigma associated with dementia, but Eller has found that it is particularly pronounced in Asian American communities. According to her, this stigma can play a large role in discouraging families from seeking care. "Bringing concerns of an older family member's memory to their attention and asking them to see a specialist is a very delicate conversation for anybody," Eller says, "But the more definite stigma surrounding dementia seen in many Asian cultures can make these sorts of conversations particularly difficult and even less likely to take place."

The way people talk about dementia can frame people's perceptions of it, and the words used within a culture influence both awareness of the disorder and response to a diagnosis. "Alzheimer's is a disease which affects millions of Asians," says Trinh. "Yet in most Asian countries and cultures, a word does not exist to describe it." A lack of words for dementia can make dialogue with a family member and screening by a healthcare provider less likely to occur. According to Edie Yau, the director of Diversity & Inclusion at the Alzheimer's Association, 'Alzheimer's disease' translates into colloquial Chinese as 'crazy-catatonic disease'. While each individual's personal experiences factor into how they react and respond to a diagnosis, the translation's association with mental illness can make someone less likely to seek out care later. "When your mother's given a diagnosis of 'crazy' or 'catatonic', it doesn't really encourage you to reach out for help," says Eller. "Many people don't want to admit that to their communities." >>

From a structural perspective, many healthcare offices don't have the tools to effectively translate a diagnosis and help non-English speakers, such as first-generation immigrants. Because of this lack of resources, mainstream clinics often refer these people to international clinics.

However, mainstream and international clinics don't always coordinate. "Many healthcare providers refer first generation immigrants to international clinics for follow up care," says Eller. "But those clinics end up being a sort of black box – they don't know what happens to those patients afterwards." Without strong communication and referral networks between clinics, it can be more difficult to ensure that patients receive ongoing care and resources.

Cultural tradition also plays a factor. Eller has found in her research that filial piety, a sense of duty of the young to respect and take care of their elderly family members, is present in many Asian American communities. Asian Americans are much more likely to take on caregiving responsibilities for elderly relatives than any other ethnic group, and Trang Tu's story in GAPS is representative of many cases today where a child acts as the sole caregiver of a parent with dementia. While a strong tradition of responsibility and duty for the young to take care of the old can be beneficial, dementia poses challenges beyond the scope of normal aging. According to Eller, when strong convictions of filial piety translate to a lower willingness to seek out or accept help from outside sources, it often amounts to worse results for both the patient and caregiver.

The combination of these cultural factors and the lack of resources specific to Asian

American communities and languages adds up to many people not reaching out for help in the early stages. "A common trend is for people to try and do everything on their own to take care of their parents, until they burn out," says Eller. "But if they could be encouraged to reach out earlier, it might not have to come to that." Dr. Belza's team identified that the best possible outcomes for people living with Alzheimer's hinge on early detection, intervention, and management of the disease by a healthcare professional. Because the cultural and structural factors that Asian American communities experience lead to less help early on and worse outcomes, it is particularly important that these unique challenges are addressed.

The work to address these problems and create the action guide started with a project from the affiliate Healthy Brain Research Network member center at the University of Pennsylvania. In 2017, the Pennsylvania center developed messages to encourage African Americans to accompany an aging parent with cognitive changes to see a healthcare provider. Dr. Belza then launched an effort to repeat the study at member centers across the country.

"We quickly came to realize that in order to make effective messages, we needed to tailor them to different communities," says Dr. Belza. "At our center, we chose to focus on Asian American communities for our study because we have strong relationships with local Asian communities and passionate partners who share our goals."

One of these partners was the National Asian Pacific Center on Aging, who helped the UW HBRN organize Chinese and Japanese focus groups to assess the acceptability of their messaging. Analysis of the focus group data reinforced the evidence of mental health stigma and dementia care barriers such as lack of awareness in Asian American communities. Once the guide was complete, the team was awarded a Seattle Innovation Fund grant which allowed the center to effectively distribute the guide and make a real world impact. The center reached out to clinics in Seattle, such as the UW Memory and Brain Wellness Center, the International Community Health Services clinic, and Asian American-focused health care settings, such as the Asian Counseling and Referral Service and Keiro Northwest.

Since the UW Coordinating Center's outreach to our clinic last year, our team has taken actions to make our care more accessible to the Asian American community. So far, our clinic translated the *Living with Memory Loss* handbook into Chinese and Vietnamese. Making educational materials and resources more culturally appropriate is a good step along the path towards reaching inclusion and access for Asian communities. The Memory and Brain Wellness Center aims to help model our efforts for other clinics.



Raising awareness of the challenges that Asian American communities face in accessing dementia care is a necessary step towards adapting our systems and reaching better public health outcomes. To help fulfill this need, Dr. Belza's team not only aims to use their guide to raise awareness among practicing service providers, but they also hope to reach the next generation of service providers. In one example of success, Dr. Tamara Cunitz, MN, RN, of the UW School of Nursing, used the guide as a case example for her students. "It was great to see these students take our work and learn how to implement it into practice before they even start providing services," says Dr. Belza, "That's exactly what you want to happen." To her, this story is an exemplary example of how the goals of the guide were able to come to fruition.

The next challenge to tackle may be in the way ethnic data is recorded. When filling out paperwork at the doctor's office and checking the boxes for race and ethnicity, individuals might find that the options fall short of reflecting their actual



identity. The term “Asian American” encompasses over fifty subpopulations and over one hundred languages, so these generalized options mask a myriad of differences between cultures. “Lumping all these different countries, and peoples, and cultures and languages all together – it’s convenient. Culture does matter,” says Dr. Alan J. Chun, M.D. of the International Community Health Services, in his interview in *GAPS*.

This nonspecific way that clinics tend to collect ethnic information also means less information for researchers to work with. “Not just checking the Asian American box, but getting down to the specific culture people are coming from can make a big impact,” says Eller. “It can help us fill in the gaps in the data in terms of the different rates of risk for dementia between subpopulations, and also give us insight into cultural trends we might be seeing.” Valuing the differences between cultures can give researchers the resources to tease apart the risk factors for cognitive decline, and ultimately reach a more complete understanding of Alzheimer’s disease and dementia in underserved communities.

The action guide is a strong step towards educating people about the challenges Asian American communities face in accessing dementia care, but there is much work to be done in order to bridge the gaps themselves. “We believe these kinds of efforts to promote culturally relevant dementia care are vitally important,” says Marigrace Becker, MSW, Program Manager of Community Education and Impact at the UW Memory and Brain Wellness Center. “As health care and service providers become more aware of the varied cultural experiences of dementia, more people will receive the kind of dementia care they desire and deserve. We’re excited to help expand this conversation by helping to share the *GAPS* documentary with the wider community.” •

Franklin X. Faust is a research scientist who works with the UW Integrated Brain Imaging Center to interpret neuroimaging data, in coordination with ADRC researchers. He is a member of the ADRC communications team and helps with outreach.

Resources:

- Watch *GAPS*, a documentary by Peter Trinh on Alzheimer’s disease in the Asian American community. <https://vimeo.com/272863037>
- The *Asian American and Pacific Islander Dementia Action Guide for Service Providers*: <https://depts.washington.edu/hprc/resources/products-tools/aapi-dementia-action-guide/>
- UW Healthy Brain Research Network’s Coordinating Center: <https://depts.washington.edu/hprc/research/thematic-networks/hbrn/>
- The *Living with Memory Loss* handbook of the UW Memory and Brain Wellness Center is available in multiple languages: <http://depts.washington.edu/mbwc/resources/living-with-memory-loss>

Garden Discovery Walks

Savor the season — explore nature with others living with memory loss and family and friends!

**Spring 2019
First Fridays**

4/5, 5/3, 6/7

10 a.m. - 12 p.m.



Enjoy a walk through a local public garden, followed by a creative, nature-inspired project led by a registered horticulture therapist. Light refreshments provided. Our short walks are at an easy strolling pace, usually with places to rest along the way.

Walks limited to 15 participants. Locations vary by month.

FREE! Pre-registration required:

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A Life in Review: Legacy Creation through Palliative Care

By Andrew McCormick, MSW, PhD, Alumnus of the Memory and Brain Wellness Center

Each of us brings something to life and eventually many of us will leave something behind for our heirs. Most of the time we think of a bequest in terms of money or property left in our will, but a legacy can take other forms such as our history of relationships, our work accomplishments, our wisdom earned in the experience of life, and the love we share with our family members and friends. This legacy forms a bond with people we will eventually leave behind.

People with memory loss and their family members may be fearful of losing touch with aspects of life that are important to loved ones as memories fade with the advancement of Alzheimer disease's and related neurodegenerative conditions that lead to dementia. Taking time in the early stages of memory loss to review life's events, challenges, successes and failures, and what was learned along the way can be satisfying for both a person with memory loss and their family members. Collecting stories, artifacts, photographs, correspondence, and other items and organizing them can provide a focus for life review and form a legacy for those who come after us.

Legacy is a special aspect of Palliative Care

When most of us think about palliative care we often think of a sick person and the pain they may be experiencing. But palliative care is much more than pain relief and is available at any stage of life when we want to provide relief from suffering, not only suffering on the physical level, but also on the emotional and spiritual levels. Much suffering for those with memory loss comes on the emotional level in the form of fear of worsening memory loss and a withdrawal from everyday life because of some limitations in personal interactions with other people.

Alzheimer's disease and related neurodegenerative conditions are considered progressive, which means they progress, or get worse, over a period of time. Memory problems usually develop gradually, and the changes that are happening may not be readily apparent to a person. Often, people with memory loss and their family members do not want to discuss planning for the future, because the need to talk about the future seems far away.

However, the slow progress of memory loss also provides an opportunity to think about and talk about the future while a person is still able to participate in the discussions. Starting with a focus on the person's legacy can help introduce the idea of planning for the future. >>

Legacy as a Joint Activity

With the help of a spouse, adult child, another relative, or care partner, reviewing our legacy can take many forms. Probably, one of the most common methods of reviewing our lives is to flip through a photo album. Many of us, however, are likely to have some boxes with lots of photos in them. A good joint project is to put the photos in some order that tells a story. Some will want to do this chronologically starting with childhood, but others may prefer to group them by family members and friends, or around a travel topic, a long-time hobby, or religious, political, or work experiences. Today we have the option of organizing photos and other documents on a computer. We can use photos and add video and music to the project and then share it through a social media site.

There are many other ways to form a legacy. The enjoyment and playing of music can represent part of our life experience. Listening to the Oldies from a particular generation can be great fun and making a mix tape of favorite songs can involve everyone. Putting together a list of books that have had an influence on our lives and perspectives can assist in clarifying values in our life review.

Personal expression through art or a craft can help stimulate memories and provide an outlet for reminiscing and storytelling. Despite losses in memory, people can still express their creativity through color in painting, handwork such as knitting and crocheting, and light carpentry such as building a birdhouse. Art provides an avenue for expression that is in the present moment and can be shared with others.

For many people the spiritual aspect of life will be an important part of creating a legacy. Many older people can experience a deepening interest in spiritual matters with age. Others find this connection in other ways. The experience of closeness to God, nature, and the world at large including other people, both at home and across the world, can provide a feeling of connection that can feel distant at busier times in our lives. Prayer, meditation, and exploration of nature are ways to share in the spiritual part of life.

A Way to Discuss the Future Too

Embarking on this kind of legacy review of life can be a rich experience, but may also be a bit unsettling, especially if a person is not used to sharing their inner selves with others. Patience is important and taking the activities in small installments can be helpful. Saving partially completed activities will be important, and this is where the photo album, online photo collection, or social media account will be helpful. The saved components of the project can be reviewed before beginning again, and then be available whenever someone wants to look at them.

Each step in the activity provides an opportunity not only to review the past, but also to plan for the future. The legacy of a person is largely based on what he or she has valued in the past, and these values will inform their wishes for future care planning.

Beginning the process of review during an early stage of memory loss allows a person to participate in planning for themselves in anticipation of the day when they may have to rely on others to ensure they receive the care they want and avoid the care they do not want. Reflection on what we have experienced in life, what we have brought to life, and how our friends and family will continue to carry our legacy forward, may also bring some solace when we confront the mystery of life and the changes that come with aging.

The following list of questions can help you start thinking about your own approach to creating a legacy.



Legacy Questions

A glimpse into your life is a gift.

Sharing your thoughts and experiences is a wonderful way of telling your family and friends that you love them. Ordinary lives often contain extraordinary moments, actions, and stories.

What are your most strongly held beliefs? Did any of your beliefs change as you aged?

What are your hopes for yourself and others?

What are your concerns for yourself and others?

Where did you get inspiration in life? What motivated you?

Who influenced you or was there an event that shaped you?

What did you struggle most in life?

What did you desire most in life?

Why did you marry? Why did you not get married?

How many children did you have? Did you choose not to have children?

How did you choose your profession?

How did you choose your hobbies?

Did you ever change your views on life?

Do you have a memory from childhood that you think about or relive?

Are there life lessons you know now but wished you knew when you were younger?

What matters the most to you right now?

What do you hope to accomplish in life

What are your hopes for your loved ones?

What would you like to be remembered for after you die?

Courtesy Carol Kummet, LICSW, MTS, UW Medical Center Palliative Care



Busting Myths about Alzheimer's Treatments and Diets

By Franklin X. Faust

In 1965, a group of scientists serendipitously discovered that injecting aluminum salts into rabbits produced cognitive deficits and tangles in brain cells resembling those seen in human cases of Alzheimer's disease. The finding mobilized the scientific community to investigate the connection between aluminum exposure and Alzheimer's disease, spurring a new era of research. As word spread, many people became worried that everyday items they used in their homes could be putting their families at risk. But throughout decades of research, scientists failed to find a convincing link between aluminum exposure in humans and Alzheimer's disease. Today, Alzheimer's disease experts and researchers classify aluminum in household products as an unlikely risk factor and a dead-end in Alzheimer's research. Even though the aluminum theory has been disputed and criticized for decades, a fear of aluminum still persists in public thought and on the labels of personal care products.

The years of aluminum research demonstrate that even the most popular scientific theories can be wrong. The scientific method is designed to produce the most accurate insights possible, but re-testing and peer review doesn't happen overnight. "For a disease as serious and complex as Alzheimer's, it's understandable that people want answers and guidance sooner than scientific knowledge can progress," says Dr. Paul Crane, MD, MPH, physician and researcher at UW Medicine. "Alzheimer's disease research is a rapidly growing and changing field. If real scientific understanding is not distinguished from misleading, and often pseudoscientific claims, it can be nearly impossible for people to navigate on their own."

Popularized books and articles reporting on science's advancement often use phrases such as "Scientists have proven that..." or, "Scientists have found this to be true..." People want simple, clear-cut answers, but a serious look at the scientific evidence behind some popular claims suggests that the truth is complicated. In an article recently published in *JAMA*, researchers in the Department of Neurology of University of California, San Francisco document a rise in false claims about supplements and 'pseudomedicine' for dementia and brain health. As more 'pseudomedicine' makes its way into the public sphere, keeping a critical eye for "scientific" claims that extend past reliable scientific knowledge is particularly important. From gluten and carbohydrates, to coconut oil and the ketogenic diet, UW scientists can help us to set the record straight on their relevance to brain health and dementia risk.

Guidance on Gluten

A few years ago, the New York Times best-seller *Grain Brain: The Surprising Truth about Wheat, Carbs, and Sugar – Your Brain’s Silent Killers* cited Dr. Crane’s 2013 research published in the *New England Journal of Medicine* titled *Glucose Levels and Risk of Dementia*. Dr. Crane’s study found an association between higher levels of blood sugar and a higher risk of dementia, and the author pointed to Crane’s study to claim that gluten, sugar, and carbohydrate consumption increase dementia risk. The idea is that because gluten-heavy grains tend to have a higher glycemic index than fruits and vegetables, and therefore produce larger changes in blood sugar, eating more grains will increase your risk for dementia. But Crane does not view his study as evidence in support of these dietary claims.

Blood sugar is different than dietary sugar - diet, genes, and exercise all interact to determine how a person’s blood sugar may spike after a big meal. “Normal Seattle diets were driving the differences in blood sugar we were seeing along with differences in genetics and other metabolic factors such as how much exercise people were getting,” says Dr. Crane. “Our study found an association between higher blood sugar and dementia risk. That’s not at all the same thing as finding that differences in gluten, sugar, or carbohydrate consumption were causing the association that we’d found.” The study was simply not designed to account for the differences in the diets of the participants. Claiming causation from association is a classic example of flawed logic, and any recommendation for intervention based on an associative, non-specific finding deserves significant scrutiny.

While it is generally likely that eating too much sugar and carbohydrates is unhealthy, and true that even people without celiac disease can have gluten sensitivities, evidence shows that cutting out all three completely is potentially dangerous for heart health. As suggested in a study published in 2017, people who adhere to gluten-free diets may consume fewer beneficial whole grains, which puts them at greater risk for cardiovascular disease. Not all claims, or grains for that matter, are created equal.



Paul Crane, MD, MPH

Coconut Oil, MCTs, and the Ketogenic Diet – A Need for Nuance

Coconut oil has been touted by some as a groundbreaking supplemental treatment for Alzheimer’s disease, but the scientific evidence suggests caution. For a miracle cure, coconut oil has a very high concentration of something most scientists and dietitians say people should try to avoid: saturated fat. According to Dr. Angela Hanson, MD, geriatrician and researcher at UW Medicine, “In general populations, high intake of saturated fat seems epidemiologically linked to increases in both Alzheimer’s disease and vascular dementia, and mouse models have given insight into some of the mechanisms behind those links.” A healthy heart promotes a healthy brain, and risk factors for cardiovascular disease also put one at greater risk for dementia.

A recent study by the American Heart Association found through randomized, controlled trials that a switch from saturated fat to unsaturated fat reduced cardiovascular disease by almost 30%, which is comparable with the risk reduction seen with statin treatment. Overall, the high concentration of saturated fat in coconut oil makes the claim for coconut oil as an effective Alzheimer’s disease supplement seem unconvincing. “There’s no clinical trials on coconut oil, and the evidence behind it is mixed,” says Dr. Hanson. “While using it every now and then is probably fine, I would be very cautious towards taking large doses of coconut oil for any reason.”

All that saturated fat begs the question - what is it about coconut oil that has some people claiming its potency as an Alzheimer’s disease treatment? In addition to its high concentration of saturated fat, coconut oil contains medium chain triglycerides (MCTs). MCTs are actually connected with the ‘ketogenic diet’, which is also touted as beneficial for the Alzheimer’s brain. The goal of the ketogenic diet, a diet very high in fat and low in carbohydrates, is to restrict carbohydrates to the point where the body switches into ketosis, a metabolic process usually triggered under starvation conditions. In ketosis, the liver converts fats into alternative fuel sources called ketone bodies. “These ketones seem to be able to enter the areas of the Alzheimer’s brain that can no longer access or utilize glucose for fuel,” says Dr. Hanson. “The idea is that more ketones to these brain regions will keep neurons fueled and promote better brain function.” While treating some neurological conditions with ketones or a ketogenic diet have shown beneficial effects, differences in outcomes between sub-populations highlight the need for a more nuanced view.

In fact, small clinical trials have suggested that MCTs are helpful for some patients with Alzheimer’s disease, but not others. Dr. Hanson’s own research suggests that the efficacy of the treatment may depend on a person’s genetics. “Carefully controlled ketone studies have not benefitted carriers of the APOE4 gene variant,” she says. “In one case, APOE4 carriers got worse in the short-term and may have actually been harmed by ketosis.” >>



Angela Hanson, MD

The APOE4 gene variant is the strongest known genetic risk factor for developing Alzheimer's disease after age 65, meaning that those who carry the APOE4 gene have been shown to be at a greater risk of developing the disease. Dr. Hanson has investigated the APOE4 effect on brain health outcomes from following a high-fat vs. low-fat diet. Her study found that APOE4 non-carriers had improved measures of cognition and reduced inflammation on the low-fat diet when compared to those on the high-fat diet, but that APOE4 carriers counter-intuitively performed better on the high-fat diet than on the low-fat diet. To Hanson, these findings shouldn't be taken as dietary advice. "Most people don't know their APOE4 status, so if people go on diets that are outside the norm, they could potentially be doing themselves more harm than good," she says. "We have a lot to understand still, and as a person who studies personalized medicine, there may be different diets and treatments best for different groups."

A ketogenic diet has other considerations that call its efficacy and implementation into question. Ketogenic diets have a long history of success in the treatment of neurological conditions; with studies first showing successful childhood epilepsy treatment in the 1920s. However, use of the diet to treat epilepsy in adults has been falling out of favor at UW Medicine. "Some UW Medicine physicians and dietitians have discontinued using the ketogenic diet for adults with seizures as they have not seen positive results," says Anne Linge, a registered dietitian at UW Medicine. In her own practice, Linge also cautions against following low-carb diets for long periods, raising concerns that the lack of fruit, vegetables, and grains in the diet limit the microbiome's food sources which could negatively impact the gut and brain alike.

Debra Clancy, a registered dietitian at UW Medicine, does not prescribe the diet and claims there are caveats to the potential benefits. "The ketogenic diet is a difficult diet for most people to follow. It can have lifestyle impacts as well as intolerable side-effects," says Clancy. "It's very important for people to consult with a dietitian before seriously engaging with such a diet."

Evidence for Commonsense

Because there is no cure for Alzheimer's disease, many people given a diagnosis of cognitive impairment tend towards pseudo-medicinal claims which seem to offer elements of hope. The marketing of "brain health" supplements is a huge industry, and it attracts a large audience by offering simple, pill-sized solutions to complex, frightening problems. But while many supplements claim universal cognitive benefits, they rarely have convincing evidence. A little-known fact is that supplements are not actually required to prove either safety or efficacy to the FDA before going on the market, so most supplements are only supported by limited research studies which lack strong certainty. A focus on these products and niche diets can divert resources away from lifestyle interventions that actually have strong evidence for benefitting cognition and brain health.

There's a better case for a balanced diet than for specific supplements and niche diets. "We've always been trying to find the magic pill for youth. I think a balanced diet with a variety of foods is going to be the right answer for most people's



By Lenny Larsen, the Art of Alzheimer's 'Food for Thought' exhibit. Art created at Elderwise.

long-term health," says Dr. Hanson. "We're talking about a diet that you can use to best improve your brain health over years. That diet has to be sustainable, livable, palpable to you and your culture and schedule." Dr. Hanson, Linge, and Clancy all strongly recommend a Mediterranean diet, comprised highly of fruits and vegetables with a low intake of saturated fat and red meat, or a MIND diet, which emphasizes leafy green vegetables, berries, and nuts.

"The current research is strongly in favor of the Mediterranean or MIND diets as the best option for preventing cardiovascular disease and supporting healthy aging," says Dr. Hanson. The research on these diets is not definitive, but a more complete picture is on the horizon. A randomized controlled trial is currently under way at Rush University to test the effects of MIND diet intervention on brain health, and it is projected to finish in April 2021.

A large body of evidence shows that an active lifestyle can be empowering in preventing and intervening in cases of progressive cognitive decline. According to the American Heart Association and American Stroke Association's 2018 Presidential Advisory concerning Optimal Brain Health, a number of randomized, controlled exercise intervention trials have shown beneficial effects of exercise on cognition. Unlike many diet studies, these trials show clear, causal effects of exercise on improving brain health. And while APOE4 carriers are often thought to be more likely to develop Alzheimer's disease, some studies have found that APOE4 carriers benefit even more from exercise. "It's really encouraging because it challenges the notion that APOE4 carriers have worse disease and show signs earlier," says Dr. Hanson. "These studies suggest that they have different metabolisms and routes that lead to

Alzheimer's disease, so different treatments might benefit them more or less."

Overall, when thinking about brain health it is important to remember that an ounce of prevention is worth a pound of cure. While simple solutions are attractive and are unlikely to fall out of favor, evidence suggests that there will likely need to be a diversity of solutions for ensuring brain health and preventing or reversing cognitive decline. Researchers agree that precision medicine, not pseudomedicine, is the path to a healthier society. A one-size-fits all silver bullet for the prevention of neurodegenerative disease and dementia ignores the complexity involved in improving mental health outcomes. Instead, recognizing and studying the differences in development and trajectory of disease, and optimizing tailored treatments best for different groups will put us on the right path towards ensuring pro-active treatment and optimal brain health for all. •



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Justina Bagger

Research Update

Justina Bagger, ADRC Clinical Research Coordinator, presented data from a volunteer research project with Dr. Angela Hanson and Dr. Carolyn Parsey, at the International Neuropsychological Society's (INS) 47th Annual conference in New York City, February 21 to 23, 2019. The team is looking at the validity and feasibility of using the NIH Toolbox Cognitive Battery (NTCB) for measuring cognition in a clinical intervention for a geriatric population, Dr. Hanson's Meal and Memory Study (see below). The NTCB is a collection of tests, or cognitive battery, and was released on the iPad in 2015. It tests several fields of cognition, such as memory, attention, and executive functioning.

Dr. Hanson has completed about 40% of the study visits for her Meal and Memory Study, and she aims to recruit 80 participants. In these preliminary data, the NTCB tests appear to be valid so far, meaning the tests seem to be staying true to what they are designed to do. One way the researchers confirm validity is through the tests for 'crystallized memory', or memory that should not change due to disease or age. These measures remained the same from Time 1 to Time 2, 3-5 weeks after the initial study visit. Dr. Hanson and her research coordinator, Anthony Liu, continue to collect data through research visits. Our team will continue to test the feasibility and validity of the tool as they get more data.



ARE YOU INTERESTED IN HOW DIET CAN AFFECT MEMORY?

The University of Washington is currently enrolling people for a study testing how two different meals (one high in fat, one low in fat) affect memory, blood and spinal fluid markers.

YOU MAY BE ELIGIBLE IF:

- You are age 55 or older
- You do not have Alzheimer's disease or dementia already
- You are not currently taking medication for diabetes

PARTICIPANTS WILL RECEIVE:

- Information about dementia prevention
- Participants will be compensated for their time.

Angela Hanson
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“Celebrating 25 years of collaborative research on aging and dementia”

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Please save the date for this year's Adult Changes in Thought Symposium! We hope that you will be able to join us as we celebrate 25 years of the ACT study. We are planning an exciting agenda with updates from new projects and break-out discussions to dig deep into specific research topics. The registration website and call for abstracts will open in April 2019.

Funding for this conference was made possible in part by 1R13AG057087-01 from NIA.

For any questions, please contact us at KPWA.ACTproposals@kp.org

Building Bridges with the African American Alzheimer's Community

By Alice Mukora

Alice Mukora is a Research Associate who studies the progression of neurodegenerative disease at the Allen Institute for Brain Science in Seattle. She volunteers at the UW Memory and Brain Wellness Center.

This fall, I traveled to the Knight ADRC of Washington University in St. Louis to attend a conference on African American participation in Alzheimer's disease research. Leaders in the field convened to discuss problems around effective ways to engage with and attend to the needs of the African American community and suggest effective solutions to the challenges of recruiting diverse participants in Alzheimer's research. I came away from the experience feeling empowered to take a deeper look at the challenges that dampen African American participation in health research and the impressive work that is being done to affect the health outcomes of underserved populations and increase health equity.

Alzheimer's disease, the leading cause of dementia, is a public health issue, with projections that over 13 million Americans will be affected by the disease by the year 2050. Of that population, over 40 percent of those affected will be minorities. However, these estimates are limited because of the low enrollment of minorities in dementia research. Considering the scale of the disease's impacts, the NIH has heightened the call for the research community to address the diversity of the public while developing strategies to impact Alzheimer's disease.

Much of ongoing Alzheimer's disease research does not successfully reach groups outside of the non-Latino white population. As a result, much of what we know about the disease does not necessarily reflect the diversity of those who are affected. In fact, groups which are most vulnerable to dementia have not been well represented in research, such as the African American community. The Alzheimer's Association estimates that African Americans are twice as likely to have Alzheimer's disease as their non-Latino white counterparts, but they are less likely to have received a diagnosis or treatment. They are also substantially underrepresented in research, which dims the hope of translating research findings into actionable information that benefits the health of all people. The lack of minority participation in research negatively impacts how we understand the disease and our ability to develop effective treatments or intervention.

In discussions about increasing diversity in research, a key question often arises: What are the barriers that hinder African American participation in research? "Actually, I think the better question is what barriers are being put up by the scientific and medical community that hinder African Americans from wanting to participate," says Dr. Eseosa Ighodaro, PhD, a neuroscientist and a medical student at the University of Kentucky who recently published a paper in the *Journal of Alzheimer's Disease* to address the challenges and provide considerations associated with studying dementia in African-Americans. "I think if you turn the question around and ask it that way, that puts the onus on us as a coalition of scientists and researchers to do a better job of reaching out to the African American community."

One focus of the Knight ADRC Center workshop was examining these barriers that are in place that discourage or exclude African Americans from participating in research. Mistrust arose as key factor - a disconnect between the wants of the researchers and the African American community deter people from wanting to participate. "As you are thinking about biomedical research and healthcare research, I want you to keep some things in mind. There are historical underpinnings of unethical research," said Dr. Joyce E. Balls-Berry of the Mayo Clinic, speaking at the Norman R. Seay Lecture which preceded the Knight ADRC workshop.



Alice Mukora and Jessica MacDougall, ADRC research coordinator, attended the Knight ADRC workshop.



Eseosa Ighodaro, PhD

As recently as the 1990s, physicians and scientists conducted unethical biomedical experiments on African Americans. The legacy of studies like the Tuskegee Syphilis Trials lingers in the form of distrust of the biomedical research community and the healthcare system as a whole. People are wary of the intentions of research and unwilling to merely be subjects in a study.

“1990 is not far from today,” says Dr. Ighodaro. “Some of our mothers and grandmothers, grandfathers, brothers, sisters and uncles were there when these things happened, so I think Number One in addressing the mistrust is being brutally honest in acknowledging the medical community’s horrible track record of research on African Americans.”

Even with the ability to overcome a collective memory of mistreatment, an ineffective flow of information between researchers and study participants rekindles these feelings of distrust. This can be attributed to outreach and research methods that are not culturally competent, failing to collaborate with the local African-American community and honor its values and norms. Examples include research staff that do not reflect the diversity of the population being targeted, research requirements that are inaccessible or inconvenient, and inadequate community- and patient-based engagement. “What is ultimately missing is the perceptions and lived experiences of African-Americans,” said Dr. Crystal Glover of Rush University Medical Center, also speaking at the Knight ADRC workshop, who emphasized transparency before, during, and after clinical research is being conducted in order to optimize benefits for everyone involved.

A main takeaway from the workshop was that in order to overcome these barriers, it is of the utmost importance that researchers prioritize building a mutually beneficial and sustainable relationship with a community to ensure that people are active and immersed participants in research.

The workshop offered great examples at institutions across the country where innovative methods have been put in place to rebuild trust with the local African American community. Many of these methods exude the importance of the reciprocity and meaningful presence that researchers need to establish before recruiting for clinical research. Before developing a highly successful center created to empower the local community, Dr. Goldie S. Byrd of Wake Forest Baptist asked, “What [do the people] need for us to do and to sustain their interest, not only in research?” Out of Dr. Byrd’s efforts, the Center for Outreach in Alzheimer’s, Aging, and Community Health (COACH) in Greensboro was created to help families, and help communities empower themselves around Alzheimer’s disease, Alzheimer’s management, and Alzheimer’s care. It had the effect of increasing research study participation in the area as more families became informed and educated on the disease and more organically were drawn to participate in research. This community investment methodology, which is integral to the success of COACH, prioritizes finding dignified ways to support the community beyond the pretense of research recruitment.

Alongside creating new spaces to empower the community, other institutions have made efforts to facilitate more cohesive interaction between those conducting research and the African-American community. One such method is mobilizing spaces

that are embedded into the African American community, such as churches, to do outreach that is purposeful and already tied to the community. Dr. Stephen B. Thomas, - director of the Maryland Center for Health Equity - championed “implementing effective prevention programs that are actually tailored to the community” at the workshop. In his own work with developing the Health Advocates In-Reach and Research Campaign (HAIR), he has been able to leverage the culturally-important setting of African-American barbershops and beauty salons to deliver health education and health services.



Image from the NIH 2018 National Strategy for Recruitment and Participation in AD and Related Dementias Clinical Research 2018

Dr. Thomas and his team have been able to utilize this existing infrastructure, both as a place of community-building and strong relationships between barbers and stylists and their customers. The campaign brought health professionals and health education to underserved communities and trained barbers as health advocates. This philosophy of promoting self-advocacy within the community is echoed in other methods, such as the ADRC’s commitment to recruit more diverse research and outreach staff that have connections with the community. Sometimes the lack of diversity in research participation is not helped by the lack of diversity among those doing the research; Alzheimer’s disease researchers and medical providers. Substantial relationships are built when those who are a part of the community are involved in contributing to finding a solution to the health problems that affects them and their neighbors.

When dealing with a disease that touches every community, we need comprehensive research to understand its impacts on the health and well being of all. The dearth of African-American representation in Alzheimer’s disease research is a problem with many complexities, and innovation will be the impetus to address and rectify this imbalance. This innovation should be well thought out and purposeful, but it also must be dynamic and change as needed.

“Not only must participation reflect the current diversity and demographics of our region, but we also must anticipate future demographics and consider future community needs,” said Jessica McDougall, ADRC research coordinator, who also attended the Knight workshop.

On this journey, I have been humbled and inspired by the work being done by the many Alzheimer’s Disease Centers represented at the workshop to adapt and accommodate changing needs, and I am excited to see how these philosophies can be expanded to other underrepresented and underserved groups in research. •

COMMUNITY UPDATE: Dementia Friends in WA State has started!



Dementia Friends is a global movement working to challenge stigma surrounding dementia. Several groups of Washington's first Dementia Friends Champions have already completed their training. These dedicated volunteers will deliver 90-minute informal talks about dementia and what people can do to create more supportive communities for people living with dementia.

We are pleased to pilot this campaign in King and Yakima Counties this year, on behalf of the Dementia Action Collaborative (DAC). Thank you to Alisa Tirado Strayer (far left), Social Work Practicum Student of the UW Medicine Memory and Brain Wellness Center, for her work as a Master Champion on behalf of the DAC. Learn about Dementia Friends: <https://dementiafriendsusa.org/>

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. To donate online, please visit www.supportuwmedicine.org/adrc.

Dimensions Magazine: To give feedback about this edition of *Dimensions*, or to request free hardcopies, please contact Genevieve Wanucha at gwanucha@uw.edu or 206.685.1304



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MODEL-AD ANNUAL SYMPOSIUM

This event is co-hosted by Sage
Bionetworks and the University of
Washington's Alzheimer's Disease



 SageBionetworks

Modeling Across Stages of Alzheimer's Disease

Discuss the use of new and improved mouse models of Alzheimer's disease to further the understanding of molecular risk and resilience.

Model Organism Development & Evaluation for Late-Onset Alzheimer's Disease (MODEL-AD) is a consortium established by the National Institute of Aging, consisting of Indiana University, The Jackson Laboratory, the University of Pittsburgh, Sage Bionetworks, and UC Irvine.

Join the conversation!

WHEN

May 9, 2019
9 AM - 5 PM

WHERE

University of Washington
SLU Campus, Orin Smith Auditorium
850 Republican Street

If you have questions about the event,
contact Zoë Leanza at zoe.leanza@sagebase.org



From City Hall to the Capitol Building: The Arts and Alzheimer's Awareness

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

Early this year, Alzheimer's awareness made an artistic splash at two iconic Washington State buildings! At Seattle's City Hall, the Art of Alzheimer's presented *The Artist Within* – 49 fascinating pieces of art created by 7 individuals with dementia. The vibrant paintings, paired with stories about the artists, showcase the creative impulse that remains or can even be enhanced in the midst of dementia.

Much of the art was created in watercolor painting workshops led by Elderwise, a local non-profit that facilitates creative exploration for persons with dementia. Featured artists include Julia Blackburn, Rosemary Freeman, Gloria Kinney, Jane Kippenhan, Pat Kristoferson, Lenny Larson, and Rafe Schwimmer.

The opening event on January 8 included talks by partners at the Alzheimer's Association, Seattle Office of Arts & Culture, and the UW Memory & Brain Wellness Center, and opportunities to meet the artists and their families. After two months at City Hall, the exhibit will tour across the state through the end of 2020, raising Alzheimer's awareness along the way.

Meanwhile, on February 19, a one-day photo exhibit called *Picturing A New Dementia Story* captured public attention at the Washington State Capitol Building. The purpose of the exhibit was to promote positive and respectful images of persons with dementia to challenge stigma.

Organized by the Dementia Action Collaborative, a group working to implement the *Washington State Plan to Address Alzheimer's Disease and Other Dementias*, the exhibit included two local photo collections.

One, called "Living Your Best Life," shows people enjoying a variety of local dementia-friendly programs such as museum gallery tours and neighborhood walking groups. Displayed at the Alzheimer's Association 2018 Discovery Conference, the photos serve as a reminder that persons with dementia remain a vital part of the community and deserve the opportunity to stay engaged.

The other collection, "Living with Memory Loss: In Our Own Words," includes photo portraits with messages from members of the Gathering Place, an early stage memory loss program at Seattle's Greenwood Senior Center. By answering the question, "What do you want the world to know about your experience living with memory loss?," members aimed to build understanding and respect. The portraits can be viewed in a short documentary: www.phinneycenter.org/memoryloss-film.



On February 19, a one-day photo exhibit called *Picturing A New Dementia Story* captured attention at Seattle City Hall. Photo courtesy Alzheimer's Association WA State Chapter and Phinney Neighborhood Association.



MBWC's Marigrace Becker and Dr. Cheryl Townsend Winter, Chair of the Public Awareness & Community Readiness Subcommittee stand ready to answer questions at the *Picturing A New Dementia Story* exhibit at Seattle City Hall.



Lenny Larsen is one of the featured artists of *The Artist Within* 2019 exhibition at Seattle City Hall. Art created at Elderwise. Photo courtesy Elderwise.

Springtime Events to Help Us Re-Frame Dementia



Book Reading: Mike and Me: An Inspiring Guide for Couples Who Choose to Face Alzheimer's Together at Home By Rosalys Peel

Join Providence ElderPlace, Seattle Public Libraries, the Alzheimer's Association and UW Memory & Brain Wellness Center for this event with author and former caregiver Rosalys Peel. Hear selections from her book, which describes ways she and her husband Mike coped, learned and grew throughout the course of his experience with Alzheimer's disease. A free event.

Date: Wednesday, May 1

Time: 4 – 6 p.m.

Location: Providence ElderPlace Seattle

4515 Martin Luther King Junior Way S, Suite 100, Seattle, WA 98108

RSVP by April 26 to Jill.Leon@providence.org

Re-Framing Dementia: An International, Interdisciplinary Conversation

Join UW Memory & Brain Wellness Center for brief presentations and Q&A with international panelists representing the fields of neurology, theology, and social citizenship. Discover new perspectives on what it means to live well with dementia. Panelists include John Swinton, PhD, Chair of Divinity and Religious Studies at University of Aberdeen, Dr. Deborah O'Connor, founding director of the Centre for Research on Personhood and Dementia at the University of British Columbia, and Dr. Thomas Grabowski, director of the UW Memory & Brain Wellness Center and UW Alzheimer's Disease Research Center. A free event.

Date: Saturday, May 11

Time: 4 – 6 p.m. followed by hosted reception

Location: Harborview's Research & Training Building Auditorium
300 Ninth Ave, Seattle 98104.

RSVP by May 8 to Marigrace Becker, 206-744-2017
mbecker1@uw.edu.



Images by Abbie Paulhus



FREE FORUM

**MEMORY LOSS
&
ALZHEIMER'S**

MAY 1, 2019 | 1:30-4:00 PM

**CENTRAL AREA SENIOR CENTER
DINING HALL
500 30TH AVE S. SEATTLE, WA 98144
QUESTIONS? CALL 206-726-4926**



Learn from experts about: Alzheimer's and other dementias, What we know about them, Legal concerns & legal resources, Tips on keeping the brain & body healthy, and Free dementia-friendly community programs and activities

A Second Chance

Nothing is pre-ordained
And nothing happens twice,
But our minds have developed
Over millennia.

Like rough rocks in a fast-moving river,
We seek rest, comfort and familiar surroundings.
But, rushing waves of time carry events
That dash against us,
Lift and roll and tumble us
Against others that are as hard,
And, truth be known, as vulnerable as we are.

With every churning roil of time's spinning river
We are lifted, moved, and exposed to new vistas.
And, as you certainly have learned,
Each lift and turn leads to a new collision.

This is education and development.
First, the thrill of being carried,
Swept away from the old and mundane.
Then, drawn and carried in a glory of movement,
We fly into yet another striking, crunching meeting
With endless varieties of forms, alive and inert.

It takes time,
But after much development
We begin to accept that every experience
Brings insight and change.
Not always do we love the process,
Until, many years later we say,
"That was a rare and rich time;
I wonder what else I will find?"

David Leek

Empty Hands

Are the clouds trails of handwriting in the sky?
Is the wind a call to dream?
Always and forever I look to see
What is in my hands.
But, no sooner do I turn them over,
Palms up, fingers splayed,
And I find only emptiness.
Praise and gratitude for that!

Emptiness; openness,
Fecundity at its inception.
An invitation to the unknown
To sacrifice its anonymity and
Be seen, be felt, be known,
If only for a moment, and a moment, and a moment
That never stops filling,
That never stops emptying,
That is an endless quaff
Always sliding smoothly down the throat of time.
We never are outside of it, until,
One day,
Time disappears,
And, curiously,
So do we.

David Leek

About the Poet David Leek is a local community member who lives in Seattle his beloved wife, Ania. He is diagnosed with early-onset Alzheimer's disease.

Arts and Creativity Showcase

These artists shared their vibrant creative work at the 2018 Frontotemporal Dementia (FTD) Education Day held by the UW Memory and Brain Wellness Center.



“Night Sky” by Sandy Howe



“Quilt” by Graciela Bravo Black



“Take Me Under Your Wing”



“Fall Colors” by Gary Hollrah

Read more about FTD Education Day and find FTD info and resources: <http://depts.washington.edu/mbwc/news/article/ftd-education-day-resources>

Thank you to our partners, the Association for Frontotemporal Degeneration, Rosewood Courte Memory Care, and the Verdant Community Wellness Center in Lynnwood, WA.

The UW MBWC offers quarterly events that provide an opportunity for people and their families touched by specific types of dementia to connect, learn and share resources.

Schedule of 2019 MBWC Resource & Education Days: <http://depts.washington.edu/mbwc/events/community-events-programs>

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UW Medicine

MEMORY & BRAIN
WELLNESS CENTER