

HORIZONS



Knight ADRC and the Memory & Aging Project

Spring 2023

INSIDE:

Equity for African
Americans in
Alzheimer Disease

Helping Children
Understand
Alzheimer Disease

WashU Alzheimer
Researchers Fund
Research Progress

IN THIS ISSUE

- 3 Letter from the Director
- 5 Equity for African Americans in Alzheimer Disease
- 10 WeSHARE: Washington University Study of Having AD Research Results Explained
- 11 Helping Children Understand Alzheimer Disease
- 14 Research Funding
- 14 WashU Alzheimer Researchers Fund Research Progress
- 15 Caregiving in the U.S.

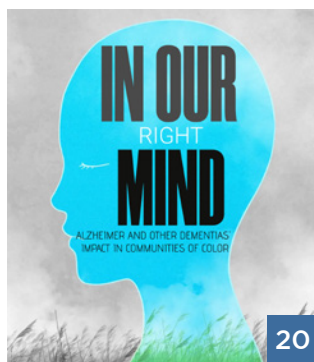


5

- 16 New Alzheimer Disease Prevention Trial in Young People Focuses on Inherited Alzheimer Disease up to 25 Years Before Expected Dementia Onset
- 17 Leqembi Approved by FDA
- 18 Spotlight on Faculty, Staff and Volunteers
- 20 Knight ADRC Presents Screening of “In Our Right Mind”
- 21 Staying Physically Active with Alzheimer Disease
- 23 Understanding Different Types of Dementia



11



20



21



22

HORIZONS is the newsletter of the Charles F. and Joanne Knight Alzheimer Disease Research Center (Knight ADRC) – a research program in the Department of Neurology, Washington University School of Medicine, funded by grants from the National Institute on Aging and private donations. The Knight ADRC supports and promotes interdisciplinary research on Alzheimer disease. The Memory and Aging Project (MAP) – the clinical research office of the Knight ADRC – provides expert clinical assessments of cognitive functioning in normal aging and dementia. Knight ADRC leadership:

- John C. Morris, MD** – Director, Knight ADRC; Director, MAP; Administration and Clinical Core Leader
- Krista L. Moulder, PhD** – Knight ADRC Executive Director and Associate Director
- David Holtzman, MD** – Knight ADRC Associate Director (assuming the role of ADRC Director 7-1-23)
- Randall Bateman, MD** – Knight ADRC Associate Director

- Carlos Cruchaga, PhD** – Knight ADRC Associate Director; Genetics and High Throughput-Omics Core Co-Leader
- Joyce Balls-Berry, PhD** – Health Disparities and Equity Core Leader
- Tammie Benzinger, MD, PhD** – Imaging Core Leader
- Andrea Denny, JD, MSSW** – Outreach, Recruitment, and Engagement Core Leader
- Suzanne Schindler, MD, PhD** – Fluid Biomarker Core Leader
- Celeste Karch, PhD** – Biomarker Core Leader
- Richard Perrin, MD, PhD** – Neuropathology Core Co-Leader
- Susan Stark, PhD, OTR/L** – Research Education Component Co-Leader
- B. Joy Snider, MD, PhD** – Research Education Component Co-Leader; Director, Knight ADRC Clinical Trials Unit
- Chengjie Xiong, PhD** – Data Management and Biostatistics Core Leader

Dear Memory and Aging Project Participants, Family Members, Faculty, Staff, and Friends

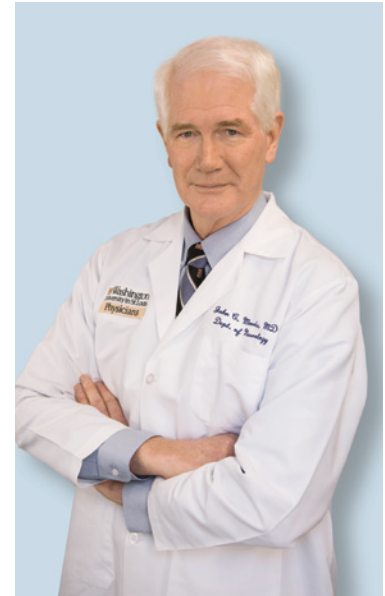
As we move further into 2023, we are grateful to be back at full capacity in the Memory and Aging Project. We missed you. After all the pandemic-induced changes of the past few years, I would like to reflect on the updates and accomplishments from 2022.

In May of 2022, I was humbled to be honored with the inaugural Beacon of Hope Award at the annual Affair to Remember Gala by the Greater Missouri Chapter of the Alzheimer's Association. I accept such awards knowing that any successes I have achieved in my career come because of the dedication of our research volunteers who have spent hours, and in many cases years, contributing to advances in the science and knowledge of Alzheimer disease (AD). The faculty and staff working at the Knight ADRC play a tremendous role as well.

We are in a hopeful place in the Alzheimer disease therapy world. In 2021, there was the controversial approval of a new disease-modifying drug called aducanumab. Aducanumab came with a hefty price tag that Medicare decided not to cover. Moreover, many physicians decided not to prescribe the drug to their Alzheimer dementia patients as there has been insufficient evidence to date that the drug provides clinical benefit. A closely related drug, lecanemab, however, has reported modest clinical benefit (ie, slowing of the rate of dementia progression) and gained accelerated approval from the Food and Drug Administration (FDA) in January 2023. We at the Knight ADRC are hopeful that the costs of this new medication will be covered by Medicare and other insurers and provide clinical benefit to people living with Alzheimer disease. The FDA is scheduled to report its decision about full approval of lecanemab in July.

There were other exciting developments in 2022. A study led by Randall J. Bateman, MD, the Charles F. and Joanne Knight Distinguished Professor of Neurology, suggests that measures of the level of the protein amyloid-beta in the blood have the potential to help identify people at risk for AD. Ideally, a blood-based screening test would identify people with Alzheimer-specific changes in their body years before they could be diagnosed in a clinic. While the research is still early, the findings are the foundation for a rapid and inexpensive

blood-screening test to identify people at high risk of developing Alzheimer disease, while also being cheaper and less invasive than PET scans or a lumbar puncture. Blood tests developed at Washington University and elsewhere are now also approved (but not yet generally covered by insurance) for use to determine the presence of proteins associated with AD in people with symptoms of Alzheimer disease.



You would likely stop reading if I enumerated all the exciting research currently happening at the Knight ADRC! However, I can tell you that besides making improvements in areas like the use of brain imaging, spinal fluid, blood samples, driving, falls, exercise and sleep to teach us about Alzheimer disease, we are now also looking at the gut microbiome and life-course factors like discrimination and lived environments to learn more about how they may contribute to the disease. It is an optimistic time to be involved in AD research, and we hope you feel a part of each new development.

There are many ways to stay updated on all the work happening at the Knight ADRC and for you to keep us updated on your research experience. You can:

- **SHARE:** Your feedback helps us provide the highest quality research experience. If you found something that was not right, we want to know so we can make it better. If you have a great experience, it helps us to know that as well. Please voice your suggestions, concerns, or praise by

Continued on page 4

LETTER FROM THE DIRECTOR *Continued from page 3*

sending an email to MAPfeedback@wustl.edu, by completing an anonymous online form at KnightADRC.wustl.edu/feedback, or by leaving a message at 314-273-1014. We love hearing from our family of participants and value your opinions!

- **REFER:** The prevention and cure of Alzheimer disease depends on research volunteers like you who contribute so much to our studies. We ALWAYS need more volunteers! Please speak with your friends and family members to interest them in Memory and Aging Project participation.
- **LEARN:** We enjoy giving community talks about Alzheimer disease. We do so without charge and would be happy to come and talk to your group, faith community, class, or organization. Contact Jennifer Phillips at 314-286-2882 or phillipsj@wustl.edu to make arrangements.
- You can attend a monthly lecture series via zoom, designed particularly with Knight ADRC participants in mind called 3rd Thursday. You can find the series at <https://knightadrc.wustl.edu/center-events/3rd-thursdays/> or contact Jennifer Phillips at 314-286-2882 or phillipsj@wustl.edu.
- **TRAVEL:** We know that transportation issues can occasionally be a barrier to research participation. If you are concerned about getting to our office, please contact us, as we may be able to assist.
- **VISIT:** There is news about Alzheimer disease research and services nearly every day. We make it easy to find all of the information in one place: on the Knight ADRC website. Visit and bookmark alzheimer.wustl.edu for daily articles, interviews, media clips, and more. You can also follow us on Facebook and Twitter.

Above all, we are always here to answer questions and provide support to anyone touched by AD. We are



John Beuerlein (left) of Edward Jones presents the inaugural Beacon of Hope Award to John C. Morris, MD (right). Dr. Morris is accompanied by his wife, Lucy Morris, MD (center).

proud to be a part of the powerful momentum to end this disease for good.

Respectfully,

John C. Morris, MD
Friedman Distinguished Professor of Neurology and
Director, Knight Alzheimer Disease Research Center

New Location!

Our community partner, the Alzheimer's Association - Greater Missouri Chapter, has moved. The new chapter office has relocated to 11433 Olde Cabin Rd., Ste 100, St. Louis, MO 63141. Families in need of support and information on Alzheimer and other dementias can call their 24/7 Helpline at 800.272.3900 or visit alz.org/greatermissouri

Equity For African Americans in Alzheimer Disease

For 20 years, the Knight Alzheimer Disease Research Center has worked to boost diversity in clinical trials

By Tamari Bhandari

Alzheimer disease is like two deaths, said Stephanie Griffin, whose father died of the brain disease in 2015. “It’s horrific,” she said. “First, you watch them lose the ability to talk, to think, to do any of the things they used to do. And then, to see them pass because of it? It’s just ... it’s a lot.”

Caring for a loved one with this fatal, progressive neurodegenerative disease is heartbreaking and exhausting. The challenges are particularly daunting in the African American community, where the disease is often poorly understood — despite Alzheimer’s being about twice as common among African Americans as other Americans.

Yet, African Americans largely have been left out of Alzheimer studies nationwide. For example, Aduhelm, a controversial Alzheimer drug approved in 2021, was evaluated in clinical trials involving just 19 people self-identified as Black or African American out of 3,285 volunteers.

These lower numbers reflect a failure by the mostly white research community to understand how African Americans view Alzheimer disease and participation in medical research. Washington University has worked hard to break the national pattern. In 2000, it established one of the country’s earliest groups dedicated to increasing African American participation in Alzheimer research: the African American Advisory Board at the Charles F. and Joanne Knight Alzheimer Disease Research Center (Knight ADRC). Today, African Americans make up 18% of Knight ADRC volunteers, up from 3% in 1999.

“If you only study Alzheimer’s in white people, you only learn about Alzheimer’s in white people,” said John C. Morris, MD, the Harvey A. and Dorismae Hacker Friedman Distinguished Professor of Neurology and the director of the Knight ADRC. “Look at Aduhelm. Doctors just don’t know whether African Americans will benefit from it at all, or in the same way, or have the same side effects profile, because we don’t have the data.”



Lenise A. Cummings-Vaughn, MD, gives a series of neurological tests to Stephanie Griffin as part of a trial for the Memory and Aging Project, which studies cognitive functioning as people age. Griffin’s father died of Alzheimer disease in 2015.

Alzheimer’s is a complex disease. Myriad biological and social factors influence who gets diagnosed, at what age and how quickly the condition worsens. These factors include family history, gender, education level, head injury, health conditions such as diabetes and high blood pressure, and cultural expectations around aging.

Regarding many of these factors, white and African American communities differ, rendering questionable the practice of using studies of white volunteers to guide care of African American patients. A recent Washington University research study revealed that three experimental blood tests designed to identify people in early stages of Alzheimer disease perform differently in African American individuals compared with white individuals. (A fourth test, PrecivityAD, based on Washington University technology, performed the same regardless of race.) Such tests, if standardized based on their performance in white populations, could put African American patients at risk of misdiagnosis and receiving inappropriate medical care.

Continued on page 6

No One Looks Like Me

Washington University is a world leader in Alzheimer research. Its Memory and Aging Project, one of the earliest long-term studies of the aging human brain, began in 1979 and continues today. The Clinical Dementia Rating instrument, used worldwide to gauge dementia severity, was developed at the university in the 1970s and revised by Morris in 1993. But when Morris became director of the Knight ADRC in 1998, he noted a disturbing fact: All of this celebrated research had been done in study populations that were 97% white.

“I made a commitment to include more African Americans in our studies, but I had no idea how to do it,” Morris said. “I had no real understanding of the way people in the African American community in St. Louis felt about Barnes-Jewish Hospital.”

Despite his years as a physician in St. Louis, Morris did not fully appreciate that the city’s history of segregation had marginalized people in ways that continued to be felt.

“If you only study Alzheimer’s in white people, you only learn about Alzheimer’s in white people.”

— Dr. John C. Morris

“They (potential volunteers) recalled when Barnes Hospital seemingly only accepted African American patients if they had particularly intriguing medical conditions, and when the African American outpatient clinic was in the hospital basement,” Morris said. “That was more than 50 years ago, and since then Barnes-Jewish Hospital has made efforts to treat all patients equally and with respect. But this history is still painfully remembered by many older African Americans.”



In 2005, local civil rights leader Norman Seay posed for a St. Louis Post-Dispatch portrait commemorating his March 1964 meeting with the Rev. Dr. Martin Luther King Jr. Seay, who died in 2019, worked for 20 years alongside the Knight Alzheimer Disease Research Center, to build equity in treatment.

Oblivious to the complexity of the task he had given himself, Morris started trying to recruit family members of his few African American patients. That's where he got lucky: Norman Seay, a highly regarded civil rights activist and educator, came into his office one day with his mother, a patient of Morris'. Seay agreed to volunteer.

"After Mr. Seay went through the enrollment process, he said to me, 'John, the entire time I was in your research office I did not see one person of color,'" Morris recalled. "I was so naïve. It had never crossed my mind that if we wanted people of color to feel comfortable volunteering for us, we needed to have a diverse staff. That's when I knew I was in way over my head. I asked Mr. Seay to help me and the Knight ADRC become more culturally competent. Fortunately for us, he was willing to do that."

Seay and Morris established the African American Advisory Board, with Seay as the founding chairperson. The board advises the Knight ADRC on cultural sensitivity and appropriate outreach strategies to encourage active participation by African Americans in memory and aging studies.

A National Model

African Americans make up about 20% of U.S. Alzheimer patients, but only about 2% of Alzheimer clinical trial participants. The greater Alzheimer research community has been slow to begin addressing that disparity. In 2019, the National Institute on Aging (NIA) of the National Institutes of Health (NIH) issued guidance on recruiting more diverse populations into Alzheimer studies.

By the time the NIA issued guidance, the Knight ADRC had been steadily improving its relationship with the local African American community under the advisory board's direction over nearly two decades. The board's success is so impressive that ADRCs in other cities have sent teams to study its methods and bring back ideas to apply in their own communities. The key, according to the Rev. Douglass Petty, PhD, the board's current chair, is that the board is genuinely empowered to influence how work is done at the Knight ADRC.

"It's not a 'We'll call you when we need you' arrangement," Petty said. "We function as a sounding board for all the work that's being done to build relationships with community organizations. And we're not a silent group. These are very strong individuals who don't mind using their voices. Anytime somebody comes to speak to the board, we ask questions. And our input is taken seriously. When grants are written, Dr. Morris



Washington University nurse Sarah Goddard administers an antibody infusion to Collins E. Lewis, MD, an associate professor emeritus of psychiatry, who has served for years as a healthy volunteer. He also is a member of the African American Advisory Board.

always directs the research team to get letters of support from the board members as a way of showing that they have asked for, received and incorporated our input."

Take spinal taps, for example. In this procedure, medical personnel pierce the spinal canal and withdraw small amounts of cerebrospinal fluid, a precious source of molecular clues to what is going on in the brain. But spinal taps have an undeserved reputation for being painful and dangerous, and many African Americans give them a hard pass. The board suggested that African Americans might be more willing to participate in Alzheimer studies if spinal taps are optional, not required.

The board also educates the local African American community about Alzheimer disease and the value of study participation. Recently, it produced a 30-second public service announcement with the tagline "Your participation is your power," to be aired on St. Louis-area TV stations.

"Our culture doesn't like to talk about what we consider negative things, and certainly Alzheimer's is one of those," said board member Beverley Foster. "I think it's mostly because we don't understand it. So, my goal has been to share as much information as possible. Black people are at risk because of systemic racism. And Black women are at the most risk because we live longer. That

makes it important that we know that while there is not a cure for Alzheimer's, there are things that we can do to be aware and stay healthy, independent and mobile as long as we can."

Foster, like most of the board members, volunteers for Alzheimer studies. Board members have spoken at churches, festivals and other community events about the disease and their volunteering experiences to counter the widespread wariness of biomedical research in the African American community. Griffin, who is not a board member, volunteers for ADRC studies and hosts informational sessions at her African American church. "You can't expect people to participate without acknowledging the history of unethical research involving African Americans, such as the untreated syphilis study, the HeLa cells taken from Mrs. Henrietta Lacks, and the Cold War experiments that happened here in St. Louis, Missouri," said Joyce Balls-Berry, PhD, an associate professor of neurology whose work focuses on promoting health equity.

The Tuskegee Study of Untreated Syphilis involved 400 African American men in Tuskegee, Alabama, who were led to believe they were being treated for syphilis for 40 years. In fact, they received no treatment; researchers merely observed them as the disease followed its natural, debilitating course. HeLa cells, the most widely used cells in biomedical research, are derived from cervical cancer cells taken from Lacks, a dying African American woman, without her knowledge or consent. In the 1950s and '60s, the U.S. Army blew the toxic chemical zinc cadmium sulfide into predominantly African American neighborhoods in St. Louis as part of a biological weapons testing program.

Given the history of racial injustice in St. Louis and elsewhere, persuading African Americans to trust the mostly white medical establishment has been tough.

"As a Black woman scientist, I always think about the fact that many times our voices aren't heard. How do we change that? There are a multitude of areas where this type of work will change the dynamic of health in the city of St. Louis and in the bi-state area and, hopefully, at a national level."

— Joyce Balls-Berry, PhD



Clinical research specialist Marilyn Wilson (standing) assists Rose Lea Willens during a Brain Aging Cafe at the Northside Youth and Senior Service Center. Coordinated by Joyce Balls-Berry, PhD, an associate professor of neurology, and other staff, the ongoing event includes discussions on brain health, aging, research registries and other opportunities to diversify Alzheimer care.

But Petty said that Washington University has taken important steps toward proving itself trustworthy. "After the Michael Brown situation, Washington University recognized and owned the fact that they are a part of this community and that they haven't done some of the things that they probably could or should have done," Petty said, referencing the 2014 police shooting of an unarmed, young Black man in Ferguson, a suburb of St. Louis. Brown's killing set off unrest in Ferguson and galvanized the national Black Lives Matter movement. "The university has taken concrete steps with diversity, equity and inclusion," Petty said. "So that has helped, but you never stop. You never take things for granted, because it's too easy for things to shift. You have to remain vigilant."

Where Do We Go From Here?

The Knight ADRC has been most successful at including African Americans in observational studies. Increasing African American participation in experimental studies like the Aduhelm clinical trials has been more challenging.

"There's a big difference between asking volunteers to donate blood and asking them to take a new, untested medication," said B. Joy Snider, MD, PhD, a professor of neurology who served as the Washington University site leader for the Aduhelm studies. "We definitely see

“Our culture doesn’t like to talk about what we consider negative things, and certainly Alzheimer’s is one of those. I think it’s mostly because we don’t understand it. So, my goal has been to share as much information as possible.”

— Beverley Foster,
African American
Advisory Board Member

some reluctance among our African American volunteers when it comes to receiving experimental therapies.”

Recruitment, however, is only one part of the problem, as trials often require a considerable commitment. “We may ask participants (and their caregivers) to come in once a month for 18 months to receive a four-hour drug infusion,” she said.

“Not everyone has the time or resources to do that. And for safety and study design reasons, clinical trial participants need to be as healthy as possible, other than the disease under study. Members of historically minoritized communities are more likely than white volunteers to have other health conditions that make them ineligible.”

To address these and other structural problems limiting diversity in Alzheimer studies, Morris established the Health Disparities and Equity Core at the Knight ADRC in 2020, the first such core at an ADRC in the country, he said. The core, headed by Balls-Berry, is tasked with incorporating principles of diversity, equity and inclusion into every aspect of the center’s work.

“As a Black woman scientist, I always think about the fact that many times our voices aren’t heard,” Balls-Berry said. “How do we change that? There are a multitude of areas where this type of work will change the dynamic of health in the city of St. Louis and in the bi-state area and, hopefully, at a national level.”

Norman Seay died in 2019, but his legacy of fighting for inclusion in Alzheimer research lives on in the board and in the Knight ADRC’s annual Norman R. Seay Lecture on Alzheimer disease and equity.

After more than 40 years at the forefront of Alzheimer research, Morris has begun thinking of retirement. He has taken measures to ensure that the equity work he started with Seay will continue when he steps down. Morris and his wife, Lucy, have donated \$100,000 to establish an endowment to provide ongoing financial support for the African American Advisory Board’s work.

“We can’t say we understand Alzheimer disease until we understand it in all people,” Morris said. “And we won’t understand it in all people until we start doing a better job of studying it in all people. We have a duty to provide the best possible care to all of our patients.”



Clockwise from bottom left: John C. Morris, MD, director of the Knight Alzheimer Disease Research Center (ADRC); his wife, Lucy B. Morris; Myrtis E. Spencer, community outreach coordinator for the Knight ADRC; and Norman Seay.

WeSHARE: Washington University Study of Having AD Research Results Explained

By Jessica Mozersky, PhD, Assistant Professor of Medicine, Washington University

I began working with the Knight ADRC in early 2016 on a topic that was already of great interest to Knight ADRC participants and researchers – the return of research results. It is also an area very close to my heart as I have been researching return of results – related to cancer and AD dementia – for nearly two decades. Here I will share with you a bit about the WeSHARE return of research results study including what we hope to learn from this study, and some things I have learned along the way.

Since joining the Knight ADRC, I have witnessed Knight ADRC participants' amazing dedication and commitment. Returning year after year for appointments, participants donate time, specimens, and take many tests, some of which may be stressful at times (like memory and thinking tests). It is these selfless contributions that help researchers learn more about AD dementia and how to better treat or prevent it one day.

In most cases, Knight ADRC participants do not learn the results of these tests. This is not unusual, as in most AD dementia research centers participants are not given their research results. This is often because we do not yet know the meaning of research tests results, and we are studying them to learn more. But many Knight ADRC participants have told us that they would like to know the results of their research tests. And they are not alone! Studies have shown that many people want to know their research results. However, we must make sure we do this in a way that does not harm participants or the science of AD research.

There are two concerns that have prevented return of research results to date. First, because there are currently no ways to prevent or cure AD dementia, someone learning they are at increased risk of, but may not definitely get, AD dementia may cause needless worry or anxiety. Second, a participant's performance on annual memory and thinking tests may be impacted by learning they are at increased or decreased risk of AD dementia. We need to better understand if these things happen before research results can be returned more broadly.

In January 2021 we launched the WeSHARE study to offer and evaluate return of research results. With funding for 5 years from the National Institute on Aging, the study offers all eligible Knight ADRC participants the option

to receive some of their research results. By following participants who receive research results, WeSHARE will answer important scientific questions about the impact of returning results on people's wellbeing and their annual memory and thinking tests. WeSHARE is also one way to give back to participants and recognize your contributions to research.

Although COVID-19 slowed down our recruitment, we hope that will ease soon. We have approached close to 50 people thus far to offer them their results. Interestingly, we found that about 25% of people chose not to get their results, which reminds us that not everyone wants to know this information.

In my years of research, I have learned that we need to respect people's right to know information about their future risk of developing AD dementia, while also respecting their right not to know. In my experience, people who are offered their research results often fall into one of two groups. There are some people who want to know their research results and do not hesitate before deciding. They feel strongly about reasons for wanting to know like: these results are about me, I am curious, I want to prepare or make plans for the future, or I want to let my family know. Other people do not want to know the information and their reasons include: it would cause unnecessary worry, there is nothing that I can do, I'm happy with my current life plans, or my family or loved ones would be upset.

We hope that our study will show that there are not major psychological harms for those who choose to know, and that any changes in annual test scores (if we find them) are measurable and can be accounted for in our research. We also hope to better understand those who do not want their results, and what drives their decisions not to know.

The findings from our study will allow us to expand who is offered research results and the types of research results that are offered in future, not only at the Knight ADRC but at other AD research centers in the US and beyond.

We strongly believe that the return of research results – for those who choose to know – is one small way of giving something back to Knight ADRC participants. Thank you for all you do!

Helping Children Understand Alzheimer Disease

When a family member has Alzheimer disease, it affects everyone in the family, including children and grandchildren. It's important to talk to them about what is happening. How much and what kind of information you share depends on the child's age and relationship to the person with Alzheimer disease.

Here are some tips to help kids understand what is happening:

- Answer their questions simply and honestly. For example, you might tell a young child, "Grandma has an illness that makes it hard for her to remember things."
- Help them know that their feelings of sadness and anger are normal.
- Comfort them. Tell them no one caused the disease. Young children may think they did something to hurt their grandparent.
- Talk with kids about their concerns and feelings. Some may not talk about their negative feelings, but you may see changes in how they act. Problems at school, with friends, or at home can be a sign that they are upset. A school counselor or social worker can help your child understand what is happening and learn how to cope.



A teenager might find it hard to accept how the person with Alzheimer disease has changed. He or she may find the changes upsetting or embarrassing and not want to be around the person. Don't force them to spend time with the person who has Alzheimer disease. This could make things worse.

It's important to show kids that they can still talk with the person with Alzheimer disease and help him or her enjoy activities. Many younger children will look to you to see how to act.

Doing fun things together can help both the child and the person with Alzheimer disease. Here are some things they might do:

- Do simple arts and crafts
- Play music or sing
- Look through photo albums
- Read stories out loud

If kids live in the same house as someone with Alzheimer disease:

- Don't expect a young child to help take care of or "babysit" the person.
- Make sure they have time for their own interests and needs, such as playing with friends, going to school activities, or doing homework.
- Make sure you spend time with them, so they don't feel that all your attention is on the person with Alzheimer disease.
- Be honest about your feelings when you talk with kids, but don't overwhelm them.
- If the stress of living with someone who has Alzheimer disease becomes too great, think about placing the person with Alzheimer disease into a respite care facility. Then, both you and your kids can get a much-needed break.

Adapted from the NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center

Honors and Awards



Dr. David M. Holtzman

The Foundation for Barnes-Jewish Hospital awarded the 2021 President's Achievement Award to **David M. Holtzman, MD**, the Barbara Burton and Reuben M. Morriss III Distinguished Professor and the scientific director of the Hope Center for Neurological Disorders and associate director of the Knight Alzheimer disease Research Center at Washington University School of Medicine.

The President's Achievement

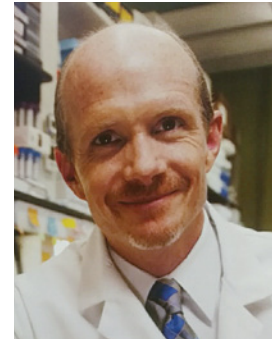
Award is given to a physician or faculty partner whose distinct and extraordinary accomplishments are advancing medicine, ensuring the delivery of world-class patient care, and educating the next generation of clinicians. Dr. Holtzman is a renowned neurologist and neuroscientist who has focused much of his research efforts over the last 27 years on trying to better understand mechanisms underlying neurodegeneration, particularly as they are relevant to Alzheimer disease. He is recognized for his pioneering work aimed at uncovering the causes of Alzheimer disease and translating an understanding of its basic biology into potential therapies.

He was chair of Washington University's Department of Neurology for 18 years, until stepping down recently to focus more heavily on research. Together with Randall Bateman, MD, Dr. Holtzman co-founded C2N Diagnostics in 2007. The company made available the first blood test for patient care that detects the presence of amyloid plaques in the brain.

After earning Bachelor of Science and Medical Degrees from Northwestern University, Dr. Holtzman completed a neurology residency at the University of California, San Francisco, where he also completed his post-doctoral research. He moved to Washington University in 1994 as an assistant professor to start his own lab focused on researching the basic mechanisms underlying neurodegenerative disease, particularly as these mechanisms may relate to Alzheimer disease.

He has received numerous awards and honors including the Potamkin Prize and the MetLife Award (both for Alzheimer disease), the Watanabe Prize in Translational Research from the Indiana Clinical and Translational Sciences Institute and the Carl and Gerty Cori Faculty Achievement Award from Washington University. He also has served as president of the American Neurological Association and was elected as a fellow of the American Association for the Advancement of Science and a member of the National Academy of Medicine and the National Academy of Inventors.

The 2023 Clinical Trials on Alzheimers Disease (CTAD) Lifetime Achievement Award in Alzheimer Disease Therapeutic Research is awarded to Randall J. Bateman, MD, in recognition for his pioneering work in Alzheimer Disease Research and Plasma Biomarkers in AD diagnostics.



Dr. Randall Bateman

Randall J. Bateman, MD is the Charles F. and Joanne Knight Distinguished Professor of Neurology, Director of the Tracy Family SILQ Center and Bateman Lab for Neurodegenerative Biology, the Dominantly Inherited Alzheimer Network (DIAN), and the Knight Family DIAN Trials Unit (DIAN-TU).

Dr. Bateman's research focuses on the pathophysiology and development of improved diagnostics and treatments of Alzheimer disease. Dr. Bateman's lab accomplishments include pioneering Stable Isotope Labeling Kinetics (SILK), furthering insights of human circadian patterns, and human in vivo control of the processing of amyloid-beta, apolipoprotein E, tau, and neurofilaments. His lab reported a highly accurate amyloid-beta blood test for Alzheimer disease amyloid plaques and also identified specific tau species in blood for accurate quantitation of amyloid pathology, has described the biology and pathophysiology of tau species in brain, CSF and blood, discovered unique soluble tau species that correlate with tau pathology, and also discovered that tau production is increased in Alzheimer disease. Dr. Bateman has received awards including the Beeson Award for Aging Research, Alzheimer's Association Zenith Award, Scientific American top innovator, the Glenn Award for Aging Research, the MetLife Foundation Award for Medical Research, the Potamkin Prize, and is a member of the National Academy of Inventors and the National Academy of Medicine. Dr. Bateman will receive the award in October at the Clinical Trials on Alzheimer Disease CTAD annual conference in Boston.

Honors and Awards

Beau M. Ances, MD, PhD, the Daniel J. Brennan Professor of Neurology at Washington University School of Medicine in St. Louis, received the 2022 Shining Star Award from the Down Syndrome Association of Greater St. Louis. Ances was recognized for his work championing the health and well-being of the Down syndrome community through his research and clinical care.

Andrew J. Aschenbrenner, PhD, was promoted to the rank of Assistant Professor of Neurology on the Research Track, effective Jan. 1, 2022. Dr. Aschenbrenner also received a \$122,302 grant from The National Institutes of Health for his project “Within-person dynamics of cognition and personality in healthy aging and Alzheimer disease.”

Ganesh M. Babulal, OTD, MSCI, was granted a change of track as Assistant Professor of Neurology on the Investigator Track, effective Jan. 1, 2022.

John R. Cirrito, PhD, was promoted to the rank of Professor of Neurology on the Investigator Track, effective Jan. 1, 2023.

Nicole Elmore, NP, was promoted to the newly created position of Associate Director of the Memory and Aging Project and is responsible for the day-to-day functioning of the MAP and will represent MAP both internally and externally in addition to Dr. Morris.

David Holtzman, MD, the Barbara Burton and Reuben M. Morriss III Distinguished Professor, was awarded the BrightFocus Foundation Scientific Impact Award for his legacy and leadership in Alzheimer research.

Jonathan Kipnis, PhD, the Alan A. and Edith L. Wolff Distinguished Professor of Pathology & Immunology and a Knight ADRC investigator, was named an academic editor of the Journal of Experimental Medicine (JEM). JEM is a monthly peer-reviewed medical journal that publishes research papers and commentaries on the physiological, pathological, and molecular mechanisms that encompass the host response to disease.

Mark McDaniel, PhD, Professor of Psychological & Brain Sciences, was selected as a 2021 Fellow by the American Association for the Advancement of Science,

the world’s largest general scientific society and publisher of the Science family of journals. McDaniel, director for the Center of Integrative Research on Cognition, Learning, and Education (CIRCLE) is being honored for distinguished contributions to the study of prospective memory and for his inspiring work on applying cognitive psychology to enhance educational effectiveness.

Erik Musiek, MD, PhD, Associate Professor of Neurology, was elected into membership of the American Society for Clinical Investigation. Membership recognizes original, creative and independent investigations in the clinical or allied sciences of medicine. Dr. Musiek studies the role of circadian rhythm in neurodegenerative diseases such as Alzheimer disease. He has discovered that body clock disturbances are an early sign of Alzheimer disease and raise the levels of damaging Alzheimer disease proteins in the brain.

Suzanne E. Schindler, MD, PhD, was promoted to the rank of Associate Professor of Neurology on the Investigator Track, effective Jan. 1, 2022 and granted tenure in the Department of Neurology



Dr. Suzanne E. Schindler

Guoqiao Wang, PhD, was granted a change of prime to Assistant Professor of Neurology and Assistant Professor of Biostatistics on the Research Track, retroactive to July 1, 2022.

Kyle Womack, MD, Professor of Neurology, was honored at the Department of Neurology 2022 Residents’ Day Symposium with the Neurology Clerkship Student Teaching Award. **Nupur Ghoshal, MD, PhD**, was also honored for Adult Neurology Teaching Excellence.

Congratulations to the following Knight ADRC faculty who were newly-elected to the National Alzheimer Coordinating Council’s Scientific Review Committee: **Ganesh Babulal, OTD, MSCI**, Assistant Professor of Neurology; **Tammie Benzinger, MD, PhD**, Professor of Radiology; **Jason Hassenstab, PhD**, Associate Professor of Neurology; and **Yan Li, PhD**, Assistant Professor of Neurology.

Research Funding

Carlos Cruchaga, PhD, Barbara Burton and **Reuben M. Morriss III** Professor in Psychiatry, received a 2022 Zenith Fellows Award from the national Alzheimer's Association. The Zenith grant program was initiated in 1991 to provide major support for investigators who have: contributed significantly to the dementia science field—Alzheimer and all other dementia research; made significant contributions to other areas of science and are now beginning to focus more directly on problems related to Alzheimer and all other dementias; and are likely to make substantial contributions in the future. Cruchaga's Zenith Fellowship Award will help fund extensive testing his lab is doing on brain cells, cerebrospinal fluid and plasma collected at the Knight ADRC. He plans to characterize, in detail, the molecular profiles of all of those samples.

Congratulations to the following investigators who were awarded Knight ADRC Developmental Project Grants. The Knight ADRC Developmental Project grant program aims to encourage investigators new to Alzheimer disease, both those who are early in their career development and those who are more senior but are new to this area, to initiate research in dementia and aging. Four grants were selected for funding from a very competitive pool of applicants and will be awarded \$100,000 per year for up to two years. The 2022 recipients are:

Laura Ibañez, PhD, Assistant Professor of Psychiatry, "Small RNA Pathophysiology and Multi-omic Interactions in Alzheimer Disease Brains"

Justin Long, MD, PhD, Assistant Professor of Neurology, "Testing Oxysterols as Therapeutic Modulators of Tau-mediated Neurodegeneration"

Victoria Fernandez, PhD, Assistant Professor of Psychiatry, "Repositioning Existing Drugs for ADAD using RNA Translational Analyses"

Kanta Horie, PhD, Voluntary Research Associate Professor of Neurology, "Blood Tau Microtubule Binding Region Identifies Tau Tangles of AD"

WashU Alzheimer Researchers Fund Research Progress

WashU Alzheimer Researchers Fund Research Progress Drs. John Morris, David Holtzman, and Randall Bateman are driving forces in Alzheimer disease research. They know firsthand the integral role charitable giving plays in advancing scientific exploration and achievement. In addition to their considerable professional contributions, the three researchers, with their spouses, also support the work of the Knight ADRC through philanthropy.

Drs. John and Lucy Morris created the John C. and Lucy B. Morris Fund for the Knight ADRC African-American Advisory Board to address the need for more diversity within study participant populations. This endowed fund supports conference and other outreach expenses. Eighteen percent of Knight ADRC study participants are African American. The African American Advisory Board is a key to attaining levels of study participant diversity and retention well above levels seen in most ADRCs nationally. The Morrises also contribute to the Harvey A. Friedman Center for Aging in the Institute for Public Health and the Memory and Aging Project within the Knight ADRC.

Dr. David and Tracy Holtzman established the TND Alzheimer Disease Research Fund and recently added to this expendable fund. The fund will support an early-career investigator's Alzheimer disease research through a project grant in 2022. The Holtzmans also support the Center on Biological Rhythms and Sleep (COBRAS), DIAN-TU, a resident travel fund, and the Dodge and Bishop Lectureship Funds within the Department of Neurology. In addition, the Holtzmans established an endowed scholarship in the School of Medicine in honor of Dr. Holtzman's parents.

In 2019, Dr. Bateman won the Potamkin Award, an internationally recognized tribute for advancing dementia research, and directed his Potamkin prize funds to establish this award in the Department of Neurology. The Batemans are also Life Members of the Eliot Society through their support of the university.

"These gifts underscore our commitment as Knight ADRC's leaders to increasing diversity in Alzheimer research as well as supporting the next generation of investigators," said Dr. Morris.

CAREGIVING in the U.S. 2020

The number of Americans providing unpaid care has increased over the last five years.*

43.5 million
2015  **53 million**
2020



18%
2015  **21%**
2020

NEARLY ONE IN FIVE (19%) ARE PROVIDING UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.**

More Americans are caring for more than one person.



18%
2015  **24%**
2020

More family caregivers have difficulty coordinating care.

19%
2015  **26%**
2020



More Americans caring for someone with Alzheimer's disease or dementia.



22%
2015  **26%**
2020

More family caregivers report their own health is fair to poor.

17%
2015  **21%**
2020

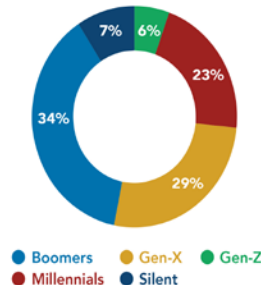


23% OF AMERICANS SAY CAREGIVING HAS MADE THEIR HEALTH WORSE.

Who are today's family caregivers?


39%
MEN


61%
WOMEN



45%
HAVE HAD AT LEAST ONE FINANCIAL IMPACT


61%
WORK

AARP
Family Caregiving™

*Provided care to an adult or child with special needs.

**The remainder of this data is based on the 19% or 48 million caregivers caring for an adult.

URL: www.aarp.org/uscaregiving DOI: <https://doi.org/10.26419/ppi.00103.002>

nac
National Alliance for Caregiving

Caregiving in the U.S. 2020,
National Alliance for Caregiving and AARP
For media inquiries, contact Media@aarp.org

New Alzheimer Disease Prevention Trial in Young People Focuses on Inherited Alzheimer Disease up to 25 Years Before Expected Dementia Onset

By Tamara Bhandari, Washington University School of Medicine

Washington University School of Medicine in St. Louis is launching an international clinical trial aimed at preventing Alzheimer disease in people genetically destined to develop the illness at a young age. Unlike most other Alzheimer disease prevention trials, this one will enroll people before the disease has taken hold—up to 25 years before the expected onset of dementia.

Called the Primary Prevention Trial, the new study will investigate whether gantenerumab—an investigational antibody under development for Alzheimer disease by Roche and Genentech, a member of the Roche Group—can clear a key Alzheimer disease protein called amyloid beta, and slow or stop the disease. Amyloid is the chief component of plaques that dot the brains of people with the disease. Many scientists suspect the disease originates from the buildup of amyloid plaques in the brain that start to develop up to two decades before symptoms of dementia begin.

“Overwhelming evidence suggests that the most effective way to slow or stop amyloid beta is to prevent it from building up in the first place, but most of the drugs targeted to this protein have been tested in people who already have at least some early signs of the disease, such as memory loss—when the disease is far enough along that reducing amyloid alone isn’t likely to stop it,” said Eric McDade, DO, associate professor of neurology and the trial’s principal investigator. “We’ll be recruiting participants as young as 18. In many ways, this trial will be a necessary test of the amyloid hypothesis, which has had a major influence on Alzheimer disease research and drug development over the past 30 years.”

The new trial involves families with rare genetic mutations that cause Alzheimer disease at a young age—typically in a person’s 50s, 40s or even 30s. A parent with such a mutation has a 50% chance of passing the genetic mutation to a child, and any child who inherits the mutation is all but guaranteed to develop symptoms of dementia near the same age as his or her parent. This certainty gives researchers an opportunity to evaluate the effectiveness of drugs designed to prevent Alzheimer disease.

Forestalling the earliest signs of disease could be game changing in the world of Alzheimer disease prevention.

More than \$130 million has been earmarked for the trial, including grants totaling an estimated \$97.4 million from the National Institute on Aging (NIA) of the National Institutes of Health (NIH), \$14 million from the Alzheimer’s

Association and the GHR Foundation, and up to \$11.5 million from longtime Washington University benefactor Joanne Knight of St. Louis and family, who have long supported Alzheimer disease research at Washington University. In addition, the university has pledged to raise an additional \$6.5 million. The trial is being conducted in close partnership with Roche and Genentech, which also is providing significant funding.

McDade and colleagues are studying about 230 participants from families that carry genetic mutations that lead to early-onset Alzheimer disease. The participants come from sites on five continents and have no or very few amyloid deposits. The trial will test gantenerumab over four years, with a goal of determining whether early treatment will prevent the buildup of the toxic protein.

“The stakes are high, and studies like this one are expensive to carry out,” McDade said. “We’re thankful for the support from many sources to make this trial possible. We’re also grateful to the families, for their encouragement and willingness to take part in trials like this one.”



*Eric McDade, DO,
Associate Professor of Neurology*

Four Things To Know About Depression and Older Adults



Everyone has feelings of uneasiness, stress, and sadness at some point during their life.

However, clinical depression is more than just feeling sad or blue. It's a serious condition that affects many older adults and requires treatment.

Signs and symptoms of depression vary from person to person.

Look for changes in your mood or your interest in participating in activities.



Depression can be treated. If you have symptoms of depression that last for more than two weeks, talk with your doctor. There are many effective treatment options, so it's important to seek help early on.



Get support from family and friends.

Though they cannot provide treatment, loved ones can help someone with depression by listening, watching for symptoms, participating in activities the person enjoys, and encouraging them to seek treatment.



A healthy lifestyle can help feelings of depression.

Staying active, eating a healthy diet, getting enough sleep, and connecting with friends and family can benefit your mental health.



Visit www.nia.nih.gov/health/depression-and-older-adults for more information about depression and older adults.

Leqembi Approved by FDA

The U.S. Food and Drug Administration approved Leqembi (lecanemab-irmb) via the Accelerated Approval pathway for the treatment of Alzheimer disease in January, 2023. Leqembi is the second of a new category of medications approved for Alzheimer disease that target the fundamental pathophysiology of the disease. These medications represent an important advancement in the ongoing fight to effectively treat Alzheimer disease, which affects more than 6.5 million Americans.

“Alzheimer disease immeasurably incapacitates the lives of those who suffer from it and has devastating effects on their loved ones,” said Billy Dunn, M.D., director of the Office of Neuroscience in the FDA’s Center for Drug Evaluation and Research. “This treatment option is the latest therapy to target and affect the underlying disease process of Alzheimer, instead of only treating the symptoms of the disease.”

Leqembi was approved using the Accelerated Approval pathway, under which the FDA may approve drugs for serious conditions where there is an unmet medical need and a drug is shown to have an effect on a surrogate endpoint that is reasonably likely to predict a clinical benefit to patients. The results of a Phase 3 randomized, controlled clinical trial supported the accelerated approval of Leqembi, based on the reduction of amyloid beta plaque, a marker of Alzheimer disease.

The prescribing information for Leqembi includes a warning for amyloid-related imaging abnormalities (ARIA), which are known to occur with antibodies of this class. ARIA most commonly presents as temporary swelling in areas of the brain that usually resolves over time and may be accompanied by small spots of bleeding in or on the surface of the brain. Some people may have symptoms such as headache, confusion, dizziness, vision changes, nausea and seizure. Another warning for Leqembi is for a risk of infusion-related reactions, with symptoms such as flu-like symptoms, nausea, vomiting and changes in blood pressure.

As specified in the prescribing information, Leqembi is indicated for the treatment of Alzheimer disease. The labeling states that treatment with Leqembi should be initiated in patients with mild cognitive impairment or mild dementia stage of disease, the population in which treatment was studied in clinical trials. The labeling also states that there are no safety or effectiveness data on initiating treatment at earlier or later stages of the disease than were studied.

Spotlight on Faculty, Staff and Volunteers

Cassandra Ward, ANP, is a nurse practitioner in the Memory Diagnostic Center (MDC) clinic's Center 40 Office. Ward grew up in Chesterfield, Missouri where she decided she wanted to be a nurse after visiting a critically ill family member in the ICU at age 10. Ward completed both her graduate and undergraduate studies at St. Louis University where she graduated with honors. Ward is married to her husband TD and they have two boys, Andrew who



Cassandra Ward

is a sophomore in college and Jack who is in 8th grade. Living on a farm in Defiance, Missouri, Ward has eight rescued mini donkeys, four horses and too many cats to count. She's hoping to develop a program to use her mini donkeys as therapy animals for people with dementia. She says, "they are much like dogs—very calm, affectionate and intelligent."

Ward has had the pleasure of spending the past ten years working with a wonderful group of physicians and support staff at the MDC. The most enjoyable part of her job is getting to know and help patients and their families through the most difficult time in their lives. The Memory Diagnostic Center's team is optimistic about new drugs to treat AD that may soon be approved. She is looking forward to many more years at Washington University School of Medicine in St. Louis.

Jack and **Rose Beckerle** are shown below with Washington University student **Kendall Johnson** at the Christmas Traditions celebration on Main St in St. Charles. The Beckerles and Ms. Johnson met through the Dementia Understanding Opportunity (DUO) Program offered by the Knight ADRC and Geriatric Outreach Group (GOG). The program pairs medical and allied health career students with volunteer mentors with early stage memory loss. The care partner is also invited to participate if interested. Together the DUOs meet once a month during the academic year to get to know each other and learn more about living with a dementia diagnosis. The program is in its 9th year at Washington University and provides a great way for mentors to share valuable experience and life advice with a student and a great way for a future healthcare practitioner to learn firsthand about living with a dementia diagnosis. Anyone interested in learning more about or serving as a mentor in DUO is encouraged to contact Jennifer Phillips at 314-286-2882.



Spotlight on Faculty, Staff and Volunteers

Taking a break from a packed schedule of research talks and poster exhibitions, Knight ADRC faculty investigators grab a bite to eat in San Diego, California while attending the 2022 Alzheimer's Association International Conference. Shown from left to right: **Joyce Balls-Berry, PhD**, **Tammie Benizinger, MD, PhD**, **Suzanne Schindler, MD, PhD**, and **Chengjie Xiong, PhD**.



Did you know that in addition to a rigorous research program, the Knight ADRC also offers support groups for care partners and individuals with memory loss? The groups meet once a month using Zoom, with one group for care partners and a separate group for people with an Alzheimer disease or related dementia diagnosis. After meeting virtually for over a year, two of the groups decided a happy hour was in order. If you are a participant in AD research at Washington University, a person diagnosed with young onset AD (diagnosed well before the age of 65) or are a care partner to one of those groups, please contact Jennifer Phillips at phillipsj@wustl.edu to learn more. Shown above at the Brass Rail in St. Charles are (top row, left to right) **Ken Albridge**, **Wes Heinz**, **Paul Stuart**, **Jim Davis**, and **Jack Beckerle**. Bottom row, from left to right: **Marica Albridge**, **Lois Heinz**, **Linda Stuart**, **Douetta Davis**, and **Rose Beckerle**.



Knight ADRC Presents Screening of In “Our Right Mind”

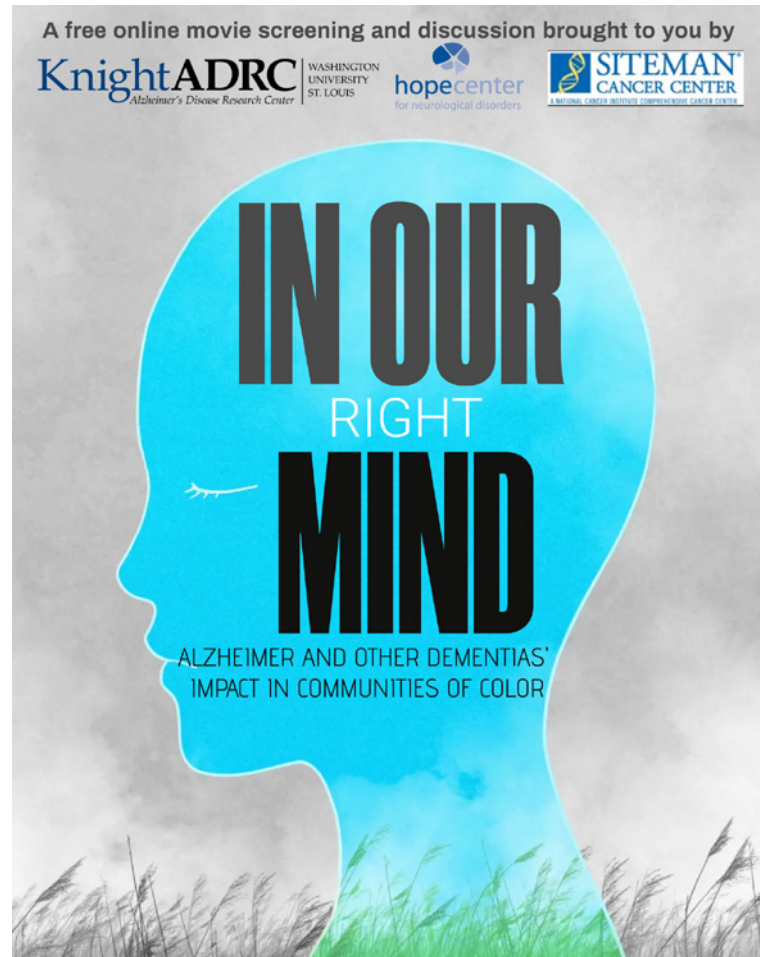
Film Director/Creator and Expert Panel Participate in the Virtual Event

The Knight ADRC was honored to host a screening of award-winning journalist, attorney, and communication strategist Renee Chenault-Fattah’s documentary “In Our Right Mind: Alzheimer’s and Dementia’s Impact on Communities of Color.” The film was an in-depth look at the effect of Alzheimer disease on Black communities and how they face the challenges and changes of the disease as families and a community. The screening was paired with a panel discussion of Washington University faculty and community leaders including **Dr. Lenise Cummings-Vaughn**, **Mrs. Stephanie Bohlen Griffin**, and **Andrea Denny**. Filmmaker Renee Chenault-Fattah also participated in the live-streamed event.

If you were unable to attend the event but would like to learn more and watch a recording, please visit our event website at <https://knightadrc.wustl.edu/center-events/community-events/#IORM>

“I just want to thank you so very much for the wonderful time that we had yesterday. Thank you and the students for your kindness & generosity and I can’t say enough about the movie. It was shown at a time when we needed to see it the most. It not only provided tremendous information re: the disease itself, but its effect on everyone involved. We had recently experienced, for about two years, the difficulty of caring for one person with Alzheimer disease, but to know that so many have the job of caring for two at the same time was surprising to us.

*Thank you again & again.
June B.*



Finding Clinical Trials

The national Institute on Aging (NIA) recently renovated the Alzheimers.gov Clinical Trials Finder website to include more information about participating in research. Visitors can learn what clinical research is, why people participate, how they can volunteer, and search the database of trials and studies to find volunteer opportunities near them.

Visit www.alzheimers.gov/clinical-trials to check out the new webpage.

Staying Physically Active with Alzheimer Disease

Being active and getting exercise helps people with Alzheimer disease feel better. Exercise helps keep their muscles, joints, and heart in good shape. It also helps people stay at a healthy weight and have regular toilet and sleep habits. You can exercise with a friend to make it more fun.

You want someone with Alzheimer disease to do as much as possible for himself or herself. At the same time, you need to make sure that the person is safe when active.

Here are some tips for helping a person with Alzheimer disease stay active:

- Help get the activity started or join in to make the activity more fun.
- Be realistic about how much activity can be done at one time. Several short “mini-workouts” may be best.
- Take a walk together each day. Exercise is good for care partners, too!
- Make sure the person with Alzheimer disease has an ID bracelet with your phone number if he or she walks alone.
- Check your television lineup to see if there is a program to help older adults exercise, or watch exercise videos made for older people.
- Add music to the exercises if it helps the person with Alzheimer disease. Dance to the music if possible.
- Break exercises into simple, easy-to-follow steps.
- Make sure the person wears comfortable clothes and shoes that fit well and are made for exercise.
- Make sure he or she drinks water or juice after exercise.

Some people with Alzheimer disease may not be able to get around well. This is another problem that becomes more challenging to deal with as the disease progresses. Some possible reasons for this include:

- Trouble with endurance
- Poor coordination
- Sore feet or muscles
- Illness
- Depression or general lack of interest

Even if people have trouble walking, they may be able to:

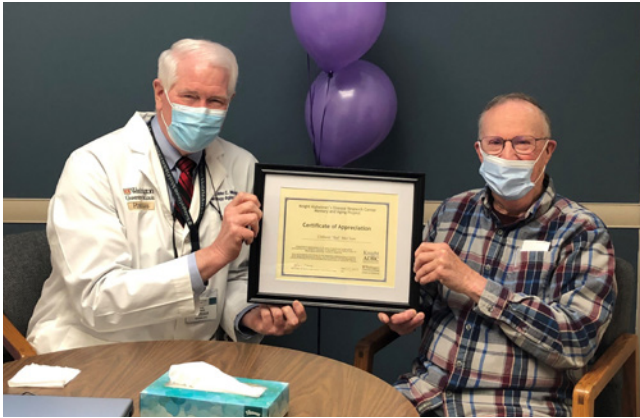
- Do simple tasks around the home, such as sweeping and dusting.
- Use a stationary bike.

- Use soft rubber exercise balls or balloons for stretching or throwing back and forth.
- Use stretching bands, which you can buy in sporting goods stores. Be sure to follow the instructions.
- Lift weights or household items such as soup cans.

For More Information About Physical Activity and Alzheimer’s, visit the NIA Alzheimer Disease and Related Dementias Education and Referral (ADEAR) Center at <https://www.nia.nih.gov/health/alzheimers>



35 Years of Memory & Aging Project Participation!



Congratulations, admiration, and appreciation were extended to **Clifford “Ted” McClure** upon completion of his 35th year of Memory and Aging Project participation. The MAP team, and **Dr. John C. Morris**, were honored to celebrate the occasion with him.

What is a Biomarker?

You probably hear us use the term biomarker when talking about Alzheimer disease diagnosis. But what does that mean? Biomarkers are measurable indicators of what’s happening in your body. They can be found in blood, other body fluids, organs, and tissues, and can be used to track healthy processes, disease progression, or even responses to medication. When combined with other tests, biomarkers can help doctors determine whether a person might have or be at risk of developing Alzheimer disease or a related dementia. Check out this great video that explains how biomarkers help diagnose dementia:
https://www.youtube.com/watch?v=n5m_qOy14VQ



Save the Date

Save the Date for the annual Memory and Aging Project Participants’ Meeting scheduled for Saturday June 3rd, 2023 at the Doubletree Westport Hotel. The program will feature a research update and breakfast will be served. Invitations are expected to go out in early May, so watch your mailbox.

Resources For Older Adults

The Washington University Friedman Center for Aging features a resource page including issue briefs on topics related to older adults and an aging society, ranging from housing to employment. Many interesting blogposts are featured on the website, including posts on ageism and other topics of interest to older adults. You can visit the website at <https://publichealth.wustl.edu/centers/aging/>

Join Us For Our Monthly Virtual Education Program

Mark your schedules to attend the Knight ADRC’s 3rd Thursday education program. Each month we feature a topic related to aging, memory and thinking changes, or other subjects of interest to older adults and professionals in the field of aging.

The events are hosted virtually via Zoom on the 3rd Thursday of each month from Noon-1pm. To learn more about the series, join the mailing list, or access the archive of recent 3rd Thursday programs, please email Jennifer Phillips at phillipsj@wustl.edu.

KnightADRC
Alzheimer's Disease Research Center

WASHINGTON UNIVERSITY
OF ST. LOUIS

3RD
THURSDAYS

AMBULATORY RESEARCH IN COGNITION (ARC)

SMARTPHONE COGNITIVE TESTING IN MEMORY RESEARCH

16

FEB 2023

TIME:
12 - 1PM

LEARN MORE ABOUT HOW RESEARCHERS ARE EXPLORING COGNITION USING A SMARTPHONE TESTING APP IN ALZHEIMER DISEASE STUDIES.



SARAH
Stout, LCSW
Clinical Research Specialist
Cognitive Technology
Research Lab, Washington
University School of
Medicine

3RD THURSDAY EVENTS ARE OFFERED VIRTUALLY THROUGH ZOOM. THERE IS NO FEE TO ATTEND.

QUESTIONS? CONTACT JENNIFER PHILLIPS AT 314.740.2958 OR PHILLIPSJ@WUSTL.EDU

Register online at <https://bit.ly/ARCSmartphonetest>

Understanding Different Types of Dementia

As we age, it's normal to lose some neurons in the brain. People living with dementia, however, experience far greater loss. Many neurons stop working, lose connections with other brain cells, and eventually die. At first, symptoms can be mild, but they get worse over time. Read on to learn more about four different types of dementia.



TYPES OF DEMENTIA

Alzheimer's Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
What Is Happening in the Brain?*			
<p>Abnormal deposits of proteins form amyloid plaques and tau tangles throughout the brain.</p> <p>Amyloid plaques Tau tangles</p>	<p>Abnormal amounts or forms of tau and TDP-43 proteins accumulate inside neurons in the frontal and temporal lobes.</p> <p>Frontal lobe Tau TDP-43 Temporal lobe</p>	<p>Abnormal deposits of the alpha-synuclein protein, called "Lewy bodies," affect the brain's chemical messengers.</p> <p>Lewy body</p>	<p>Conditions, such as blood clots, disrupt blood flow in the brain.</p> <p>Blood clot</p>

*These changes are just one piece of a complex puzzle that scientists are studying to understand the underlying causes of these forms of dementia and others.

Symptoms

<p>Mild</p> <ul style="list-style-type: none"> Wandering and getting lost Repeating questions <p>Moderate</p> <ul style="list-style-type: none"> Problems recognizing friends and family Impulsive behavior <p>Severe</p> <ul style="list-style-type: none"> Cannot communicate 	<p>Behavioral and Emotional</p> <ul style="list-style-type: none"> Difficulty planning and organizing Impulsive behaviors Emotional flatness or excessive emotions <p>Movement Problems</p> <ul style="list-style-type: none"> Shaky hands Problems with balance and walking <p>Language Problems</p> <ul style="list-style-type: none"> Difficulty making or understanding speech <p><i>There are several types of frontotemporal disorders, and symptoms can vary by type.</i></p>	<p>Cognitive Decline</p> <ul style="list-style-type: none"> Inability to concentrate, pay attention, or stay alert Disorganized or illogical ideas <p>Movement Problems</p> <ul style="list-style-type: none"> Muscle rigidity Loss of coordination Reduced facial expression <p>Sleep Disorders</p> <ul style="list-style-type: none"> Insomnia Excessive daytime sleepiness <p>Visual Hallucinations</p>	<ul style="list-style-type: none"> Forgetting current or past events Misplacing items Trouble following instructions or learning new information Hallucinations or delusions Poor judgment
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Typical Age of Diagnosis

Mid 60s and above, with some cases in mid-30s to 60s	Between 45 and 64	50 or older	Over 65
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Diagnosis

Symptoms can be similar among different types of dementia, and some people have more than one form of dementia, which can make an accurate diagnosis difficult. Symptoms can also vary from person to person. Doctors may ask for a medical history, complete a physical exam, and order neurological and laboratory tests to help diagnose dementia.

Treatment

There is currently no cure for these types of dementia, but some treatments are available. Speak with your doctor to find out what might work best for you.

Living with dementia can be challenging, but there are ways to manage it. To learn more about these types of dementia and other conditions that can cause dementia, visit www.nia.nih.gov/health/what-is-dementia.





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www.knightadrc.wustl.edu