



Alzheimer's and Cognition Center

UNIVERSITY OF COLORADO **ANSCHUTZ MEDICAL CAMPUS**

"Healthy Brain Aging Starts Here"

December 2024

Volume 6, Issue 2



Summer and Fall Highlights

As we approach the end of another impactful year, the CU Alzheimer's and Cognition Center (CUACC) reflects on a vibrant season of community engagement and education. Throughout the summer and fall, CUACC team members proudly participated in key events, including the Alzheimer's Association's Purple Gala and the Walk to End Alzheimer's, where we joined supporters dedicated to finding a cure. We also brought research insights to the CU Geriatrics Conference and hosted our own Research Education Event, welcoming research participants to learn about brain health and their contributions to our research advancements. From an important Dementia Dialogues session focused on the African American community to discussions on brain health equity more broadly, the CUACC's presence at these events highlights our ongoing commitment to accessible and inclusive care and education.

We hope the images in this issue capture the energy and dedication that guided us through this season!



In this newsletter you can expect:

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and Highlights

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Words

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Spotlight

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Groups

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Opportunities &
Upcoming Events



As we close out the year, we say a heartfelt farewell to Dr. Peter Pressman, who transitioned to a new role at Oregon Health & Science University (OHSU). We're excited for him as he begins this next chapter, advancing his work on cognitive aging and in-home technologies while moving closer to family. At the CUACC, Dr. Pressman has shaped our growth and will leave a lasting impact through his innovative work advancing clinical assessment technologies, establishing a comprehensive frontotemporal dementia program, and championing diverse perspectives in clinical research. Please join us in thanking him for his many contributions and wishing him the very best at OHSU!

Congratulations!



Congratulations to **Dr. Victoria Pelak** who was appointed recently to the role of **Executive Vice Chair of Neurology**. She was also named one of **5280 Magazine's "Top Doctors" of 2024** in Neuro-Ophthalmology! This recognition reflects her dedication and excellence in patient care.



Congratulations to **Dr. Delia Bakeman**, Assistant Professor of Behavioral Neurology and Director of the Memory Disorders Clinic, on receiving the Department of Psychiatry's 2024 **Eleanor A. Steele Award for Inspirational Teaching and Supervision**. Dr. Bakeman's research focuses on neurorehabilitation and improving access to care for traumatic brain injury (TBI) patients.

Welcome to the team!



Ece Bayram, MD, PhD
Assistant Professor



Michael Seidman, MD
Behavioral Neurology & Neuropsychiatry Fellow

In Their Own Words

In this newsletter, we are honored to share personal reflections from two individuals living with Alzheimer's disease, as told in their own words.

How I got to LIVE with Early-Stage Alzheimer's

Of course, I'll never know exactly when it all started, but here were some hints: *that time I couldn't remember the name of vegetables in the refrigerator, even though we used them frequently, *forgetting my neighbor's name after being told many times, and taking a very long time to learn my new address in Colorado.

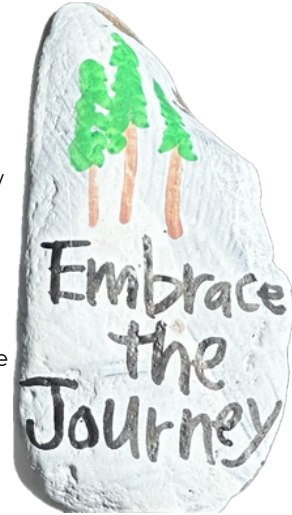
So I was just getting older, right? But then one day I was on the phone with someone I worked with on a board of directors. I wanted to write down the things she was telling me, so I would remember what needed to be done. Suddenly I panicked. I couldn't remember how to spell a very common word. I tried to sound out the first letter, thought I had it, but had no idea how to write that letter. I could not even remember what the letter looked like. I went to see my nurse practitioner a few days later about some other minor concern. At the very end of our time together, I casually mentioned what had happened on that phone call. She calmly recommended I see a Speech Pathologist.

Still very much in denial, I figured "Oh good, they'll help me with this and then I'll be all better". After an hour of testing, we both realized that this was something more than I initially thought. "Name as many animals as you can in one minute." All that my brain could come up with were dogs and cats. On some of the many tests, I did well, but it was very obvious to me that something was wrong. The pathologist carefully told me that she could not confirm a diagnosis, but asked if I wanted to know her thoughts.



The words Dementia and Primary Progressive Aphasia (PPA) came at me like a storm.

I'm still not sure how I drove home that day. When I got home, I cried in my husband's arms. For days, I felt like I was in a trance, like some bad dream that just wouldn't go away. I fluctuated between wanting to learn about PPA and what my future would hold, to wanting to do anything but that. It was hard to talk about. Hard to try to just go on with my life.



Next, I saw a Neurologist and a Neuropsychologist for more testing. I quickly learned to hate these tests, despite the kindness of the people doing them. It took me a while to realize that my biggest problem with the testing was that it made me feel "stupid." Not rational, I know, but that was how it felt. I used to supervise and train people with confidence in my abilities. I have started to feel less "stupid" with help from a therapist (which I highly recommend.) She has helped me to be more kind to myself and to focus on what I can control.

After my initial shock, I began to tell family and friends of my intention to live as fully as I can during this early stage. Eventually, I actually believed it myself. I do yoga, go to the gym with my husband, and sing with a local choral group with a friend. Music, especially with a group, has a very healing effect on me. I recently found an article about a woman in the early stages of Alzheimer's. I was so excited to read how she was living, really living, in this stage. I realized she lived nearby and was able to contact her. I am also exploring ways to reach out to others, including this, my story.

In Their Own Words

Continued

My First Steps into Alzheimer's: Denial and Diagnosis

Joan Hillebrand Alexander

At first, I denied that I was becoming more and more forgetful. When my husband said he'd already told me something, I argued that he must have been mumbling or shouting from another room. My husband shared his concerns with our Primary Care Physician. She encouraged him to be kind and help me be curious about what was going on. I came to realize that indeed, I did repeatedly ask my husband a question, forgetting I'd already asked and gotten his answer. I also found that I needed to write down more reminders for myself. I'd always kept a calendar, but I needed it to be increasingly detailed. After calls or visits with friends and relatives, I found myself writing notes after we talked so that I did not repeat myself in future conversations.

I did not know my husband had already mentioned my increasing forgetfulness to our shared physician. At my next doctor's appointment, when I mentioned my forgetfulness, she was prepared and suggested I get tested. I agreed, and she provided me with a referral to UC Health Neurology.

A UC Health specialist put me through the testing. I judged the testing procedure quite negatively. Here I was almost 70 being asked to remember how to do math and algebra I had not done since high school. Don't we all use our cell phones and calculators to do that now! Then there were those animals I was asked to identify. Certainly, I could name them; that was easy! But then, about 20 minutes later, I was asked to name the same animals from memory AND to name them in the same order! I struggled. The test went on and on like that. I did not do well, nor did I react well to the testing!

The testing indicated I had: Mild Cognitive Impairment (MCI). First reaction: What a stupid and meaningless test. Then: Darn! Yikes! "@#%"

As my memory continued to worsen, I realized something was indeed wrong! In social situations, I found it harder to follow and remember conversations. I'd forget what I'd already said, already asked, or already been told. As a result, I became more and more withdrawn, and it became harder for me to stay socially involved. I feared repeating myself and asking something I should have already known.

At home, my husband struggled with a shift in what I required of him. He was no longer to remind me of my forgetfulness. His new role was to compassionately and lovingly answer my repeated questions without frustration. He tried and got better.

Together, we committed to follow the lifestyle recommendations proven to slow cognitive decline: healthy MIND diet, regular exercise, and social interaction... even with my anxieties about how I might be perceived in those social settings.

As my memory challenges increased, my UC Health neurologist told us she suspected Alzheimer's. She suggested genetic testing to determine if I had genetic markers, and a spinal tap to look for protein markers. As frightening as the spinal tap procedure may sound, it was easy, quick, and not painful. The spinal tap confirmed early signs of Alzheimer's, and the genetic test found two copies of the APOE-4 gene. My memory problems now had a name: Alzheimer's.

The shock of the diagnosis hit me hard. Except for my memory issues, I was otherwise pretty healthy as someone in my early 70s. My husband and I were still hiking weekly in the Colorado foothills. I was still working as a successful change leadership consultant (read on for more).

In Their Own Words

Continued

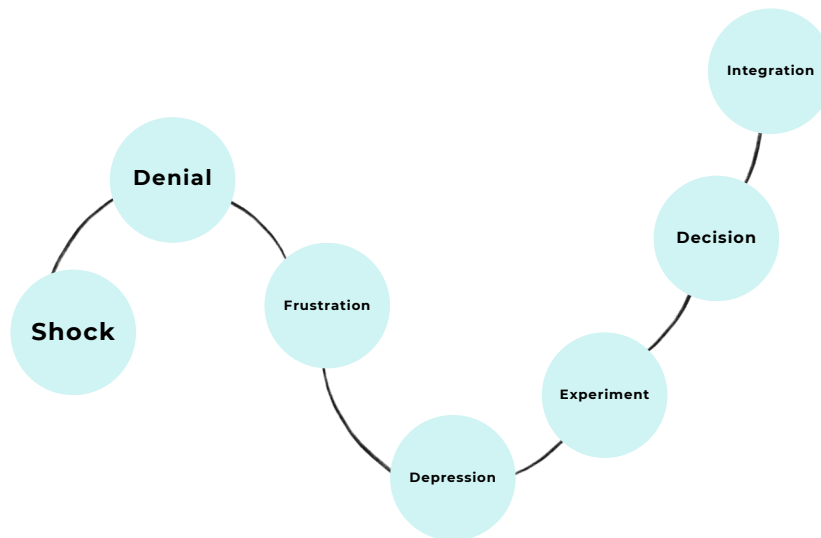
Joan Hillebrand Alexander

To help support me with my diagnosis, UC Health offered me 1:1 coaching with a CU Psychiatry social worker. I quickly accepted the offer. Managing appointments, communications, and attending video calls via the My Health Connection patient portal made the process easy. This eliminated the challenges of in-person meetings, such as driving, traffic, and parking. This also allowed my husband to join us for selected parts of our calls, when appropriate.

Looking back, I understand that I was being guided by the social worker through the steps of the “Kubler-Ross Change Curve.” This is a helpful model

that I know well. I share this model with my coaching clients as they try to lead change with their staff and within their organizations.

The Kubler-Ross model outlines a sequence of phases along a change journey: (1) Shock; (2) Denial; (3) Frustration/Anger; (4) Depression; (5) Experimentation; (6) Decision Making; and (7) Integration. Successfully moving through the steps can lead to eventual integration into a new way of being. I know from my own consulting work that without proper support, not all staff, nor change initiatives, are successful. Now, I was being supported and skillfully led through a change that I myself needed to face.



In my next article, I will share information about the valuable one-on-one support I received while working with the social worker. In another future article, I will share my experience from participating in a 10-week support group led by the same social worker.

I am successfully moving along that change curve! I look forward to sharing my experiences with you in future newsletters. You are invited to follow along with me on this journey!

Mary O'Hara, LCSW: Social Worker

With over 18 years of experience as a licensed clinical social worker, Mary O'Hara has dedicated her career to supporting individuals diagnosed with neurological conditions, particularly dementia, and their families.



Mary is a Senior Instructor at the University of Colorado's Outpatient Psychiatry Clinic.

What does a typical day look like for you?

I work with people living with a diagnosis at any stage and their family members. Some are living with early symptoms, while others come in with their families for support together. For some, I'm offering short-term therapy, helping clients manage depression or anxiety. I also work with families navigating care options and discussing when and how to introduce additional resources. Grief is a common thread in many of these sessions, and a significant part of my work is helping people understand and tend to their grief.

How did you get interested in social work?

My first introduction to social work came while I was volunteering at a non-profit in San Francisco. Seeing the many career paths and various roles that a social worker could have, I decided to go back to school. I pursued my master's degree in social work at the University of Chicago.

How did you end up specializing in dementia and caregiving?

During graduate school, I interned with the Alzheimer's Association. After graduating, I often worked many overnight shifts on the Association's 24-hour help line. This experience inspired me to focus my career on supporting people and families living with a diagnosis. After this, I went on to work at Northwestern's Alzheimer's Disease Center in Chicago where I had the opportunity to

facilitate and help research several Quality-of-Life Enrichment Programs for those living with a diagnosis.

What do you find most rewarding about working with dementia patients and their families?

I am constantly in awe of the ways people adapt to their illness and continue focusing on what is most important to them. Families, too, are incredible in how they come together to support one another. There's a common assumption that people with memory loss cannot learn new things, but I see them learning to live with this illness every day. It's humbling to witness their resilience, how they deepen their acceptance of the situation and how they support one another.

How can social work better support families living with Alzheimer's and dementia?

There seems to be a shortage of social workers who specialize in working with older adults living with neurological conditions. Social workers can run support groups, offer individual support, see couples together adjusting to a diagnosis, and help families respond to certain dementia behaviors, manage their stress, and tend to their grief.

What excites you about new developments in dementia research?

This is an exciting time in the field. In addition to clinical trials, I'm particularly interested in non-pharmacological research and caregiver interventions. Until we have more disease-modifying treatments, my hope is that we find additional ways of supporting people to live their best with a diagnosis through meaningful activity and emotional support. I hope these approaches become more mainstream. I see a future where they play a larger role in dementia care.

What else would you like readers to know about you?

It's most important to me that people and families living with a diagnosis at any stage have a supportive place to speak openly about their emotions and process their grief.

See the page 7 for current support group offerings!

Support Group Offerings 2025

Mary O'Hara, LCSW, is offering numerous new support groups through the Department of Psychiatry. An interview and intake with the CU Outpatient Psychiatry Department is required to participate. Insurance will be billed for group therapy.

PPA Caregiver Support Group



When: 5 Sessions, Monthly (January - May 2025)



Date/Time: 3rd Thursday of each month, 12:00 PM - 1:00 PM



Where: Online (Zoom)



Who: for those supporting someone living with Primary Progressive Aphasia (PPA).

Writing Through a New Diagnosis Support Group



When: 6 Weeks (February 11th - March 18th, 2025)



Date/Time: Tuesdays, 9:30 AM - 11:00 AM



Where: In-Person, Anschutz Health Sciences Building, 4th Floor Psychiatry Dept.



What: This group will use different forms of writing (e.g. letter, narrative, poetry) to process a diagnosis of Alzheimer's disease and related disorders.

Living with Early Memory Loss Support Group



When: 10 Weeks (April 8th - June 10th, 2025)



Date/Time: Tuesdays, 9:30 AM - 11:00 AM



Where: In-Person, Anschutz Health Sciences Building, 4th Floor Psychiatry Dept.



What: This group offers both education and support to those living with Alzheimer's disease and related disorders. Speakers present to group on topics of interest.

Living with Younger Onset



When: Fall 2025, Details TBD



Where: Both In-Person and Online options available



Who: For individuals living with younger onset Alzheimer's disease and related disorders.

If interested in attending any of these groups please email mary.ohara@cuanschutz.edu or call **303-724-9419**

Genetics 101: What You Should Know

For many, terms like *genotype*, *allele*, and *mutation* may seem like a distant memory from high school biology. Let's break down the basics to help you consider whether genetic testing for neurodegenerative diseases is right for you.

The Basics

Inside each of our cells is **DNA**, which contains **genes**. A person's DNA sequence is called a **genotype**, and its physical expression is the **phenotype**. Differences in our genes contribute to what makes each person unique. Changes within genes, called **mutations**, can be inherited or occur spontaneously (de novo). Often these changes will be called a mutation. However, a gene mutation does not always mean you will have a medical problem.



Three types of genetic variation:

Benign: Normal variations

Pathogenic: Causes the gene to no longer work properly.

For example, a pathogenic gene variation might mean that the corresponding protein is not folding correctly or not working correctly, there could be too much of that protein, not enough of that protein, a wrongly shaped protein, and more.

Uncertain significance: Effects unknown

Another term you might come across is **penetrance**. Penetrance tells us the chances of having symptoms if you have a disease-causing alteration of a gene. Different genes have different levels of penetrance. For example, if penetrance is 100%, then having the mutation means that you will, with certainty, have symptoms.

Genetic testing is a powerful tool, but it's a personal decision best made with support from experts.

Questions to Ask Before Testing

- Does my family have a history of neurodegenerative disease?
- Has a specific mutation been identified in relatives?
- What could genetic testing mean for my care or my family?

The Role of Genetic Counselors

Genetic counselors can guide you through the risks, benefits, and implications of testing. They're essential for understanding results, managing emotional impacts, and addressing concerns like insurance or long-term care.



Test Responsibly!

View our calendar of
[upcoming events](#)



HEALTHY BRAIN AGING

- Starts Here -

Clinical trial focused on improving cognition in people with Alzheimer's Disease

At the CUACC, we are conducting the SESAD study, a clinical trial funded by the Alzheimer's Association and the NIH, to investigate whether sargramostim (Leukine®), an immune-boosting drug, can improve cognition in people with mild-to-moderate Alzheimer's disease.

Led by CUACC director Dr. Huntington Potter, this 24-week phase 2 trial builds on over a decade of research into sargramostim. Earlier studies in mice and humans showed promising results, including improved cognition and reduced biomarkers of brain damage.

We are recruiting participants aged 60–85 with a care partner. Study procedures include MRIs, cognitive testing, and blood draws, with optional lumbar punctures or amyloid PET scans. Weekly home nursing visits are available for Front Range residents.

Contact us to
learn more
about joining
this
important
research and
view our
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on the next
page.



Contact us

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Interested in a Research Study?

Contact Neurology Research Partners at
303-724-4644 or fill out a research inquiry
form at www.cumemoryresearch.org to
learn more about our ongoing research
studies!

Thank you for reading!

Alzheimer's Clinical Trial



Do you have mild-to-moderate Alzheimer's disease?

You may be eligible for a clinical trial for an investigational drug for the treatment of mild-to-moderate Alzheimer's disease. Participants will be asked to participate in weekly visits for 24 weeks, as well as screening and follow-up visits.

In order to qualify you must:

- be between 60-85 years old
- meet criteria for mild-to-moderate Alzheimer's disease
- complete PET scans (or optional lumbar punctures) before and after study completion and receive weekly blood draws
- have a study partner willing to give daily injections after training

Check your eligibility
at www.cumemoryresearch.org

Location

After initial screenings at the CU Anschutz campus in Aurora, CO, participants will be able to have weekly home nursing visits. Occasional visits to campus during the study will be required for procedures that cannot be done at home.

Participants will receive:

- study related care and medication at no cost
- stipend to defray some costs of participation

To learn more please call: 303-724-4644

You can also email NeuroResearch@cuanschutz.edu or visit our website at:

www.cumemoryresearch.org

Health insurance is not needed for this study.



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COMIRB# 19-2727 PI: Huntington Potter, PhD v30May2024