

# ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, AND SERVICES

Virtual Meeting

**January 30 & 31, 2023**

## Advisory Council Members in Attendance

- *Non-Federal Members Present:* Cynthia Carlsson (Chair), Randall Bateman, Venoreen Browne-Boatswain, Matthew Janicki, Keun Kim, Helen Bundy Medsger, Carrie Molke, Joe Montminy, Maria Ortega, Joanne Pike, Rhonda Williams
- *Federal Members Present:* Arlene Bierman (Agency for Healthcare Research and Quality), Walter Koroshetz (National Institute of Neurological Disorders and Stroke, NINDS), Bruce Finke (Indian Health Services, IHS), Richard Hodes (National Institutes of Health, National Institute on Aging, NIH/NIA), Shari Ling (Centers for Medicare & Medicaid Services, CMS), Erin Long (Administration for Community Living, ACL), Lisa McGuire (Centers for Disease Control and Prevention, CDC), Joan Weiss (Health Resources and Services Administration), Ellen Blackwell (CMS), Tisamarie Sherry (U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, HHS/ASPE)
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Helen Lamont (ASPE)

## General Proceedings

Chair Cynthia Carlsson called the meeting to order at 12:30 p.m. Eastern Standard Time (EST) on Day 1 and 12:32 p.m. on Day 2.

### ***Welcome and Introductions***

On both days, Dr. Carlsson welcomed meeting participants and reviewed the meeting agenda.

## Federal Updates

- **ASPE.** Dr. Lamont noted that the *National Plan to Address Alzheimer's Disease: 2022 Update* was posted to the NAPA website in December 2022.

- **ACL.** Erin Long reported that ACL will release a Notice of Funding Opportunity for “Alzheimer’s Disease Programs Initiative: States and Community Programs” in February 2023, and for the National Alzheimer’s Call Center in March 2023. The National Alzheimer’s and Dementia Resource Center (NADRC) will host a webinar, “From Dementia to COVID-19: Maintaining Innovations Using Data Driven Program Decision Making” on February 23. NADRC recently released resources with information about volunteer engagement in activities related to dementia. NADRC also updated information about evidence-informed and evidence-based interventions implemented by ACL grantees. During 2023, NADRC will develop resources about addressing social isolation and loneliness, promising practices for people living alone with dementia, and a webinar on community-based dementia screenings. NADRC has hosted three webinars since November 15, 2022. Topics included successful program funding, planning, and delivery; equity programs in Hispanic and LGBTQI+ communities; and Alabama’s Providing Alzheimer’s ‘N’ Dementia Assistance (PANDA) project. NADRC will deliver presentations at the upcoming American Society on Aging and United States Aging conferences. In addition, NADRC is developing a compendium of resources developed by grantees and updating its advance planning guides. ACL expects to select new members for the Family Caregiving Advisory Council by the end of April 2023. Current council members delivered the National Strategy to Support Caregivers to Congress in September 2022. ACL’s Lifespan Respite Program continues to offer resources designed to support needs of people with dementia and their families and caregivers. ACL’s National Assistive Technology Act Technical Assistance and Training Center provides grant support to the Virginia Assistive Technology System, which provides assistive technology to people living with dementia and their caregivers.
- **CDC.** Lisa McGuire reported that CDC’s *Morbidity and Mortality Weekly Report* published an article on prevalence and characteristics of arthritis among caregivers in November 2022. Key findings were that arthritis is more prevalent among caregivers than others, and that this affects caregivers’ mobility, self-care, and independence. A CDC team published an article on characteristics of Asian American family caregivers of older adults in *Journal of Applied Gerontology*. CDC will host the National Public Health Summit on Dementia Risk Reduction May 16-17, 2023. CDC recently released a notice of funding opportunity for Building Our Largest Dementia (BOLD) Infrastructure Public Health Programs to Address Alzheimer’s Disease and Related Dementias. Applications are due March 23, 2023.
- **CMS.** Ellen Blackwell reported that CMS’s Integrated Care Resource Center offers webinars on innovative approaches to addressing health equity and caregiver support in Alzheimer’s disease and related dementias (AD/ADRD) programs. The Resource Center also held an event focused on this topic in December 2022. In January 2023, CMS released guidance on how states can expand services that address social determinants of health (SDOH). CMS also published planned

actions for improving nursing home safety and transparency, including audits to determine whether nursing homes are accurately assessing and coding schizophrenia diagnoses, and publicly displaying survey citations. CMS updated the 2023 Medicare Physician Fee Final Rule to extend availability of telehealth services, expand availability of behavioral health services, and state an intention to address payment for new codes for caregiver behavioral management training. CMS also created new codes for pain management.

- **IHS.** Bruce Finke reported that the Addressing Dementia in Indian Country: Models of Care grant program continues to support 2022 grantees, who will participate in a directors' meeting in April 2023. IHS is in the process of developing 2023 notices of funding opportunities and program award revisions. IHS's Geriatric Pilot Program supports scholars' work in detection and diagnosis, medication, and falls. IHS plans to expand this program in 2023. The Early Detection Initiative supports programs that aim to integrate dementia detection into oral health care. IHS is working with the North Portland Area Indian Health Board to develop and implement Extension for Community Healthcare Outcomes (ECHO) projects related to clinical care and caregiver support. Through the IHS Accreditation Initiative, three IHS and Tribal emergency departments have been accredited, six applications have been submitted, and one accreditation review is in progress. IHS's highest priority for 2023 is developing the nursing and community health representative workforces. IHS recently renewed a 5-year memorandum of understanding with the Alzheimer's Association, redesigned the IHS Alzheimer's grant program website, and is using its Elder Care listserv to build a community dedicated to improving care for people living with dementia and their caregivers.
- **NIA.** Richard Hodes reported that NIA has received budget increases to support its AD/ADRD work. NIA has approved 13 AD/ADRD research areas of special interest. NIA recently released new funding opportunities for AD/ADRD research. NIA supports 13 grants for research on the role of the exposome (comprehensive set of environmental exposures that affect health) on causes of and disparities related to AD/ADRD. NIA currently supports 459 clinical trials related to AD/ADRD. NIA is funding three studies to evaluate effects of lecanemab. In November 2022, NIA published a report on scientific advances related to AD/ADRD. The 2023 national Summit on Care, Services, and Supports for Persons Living with Dementia and Their Care Partners/Caregivers will be held virtually on March 20-22. The 2023 Geroscience Summit will be held April 24-26 on the NIH campus. The Butler-Williams Scholars Program will offer virtual training to junior faculty and researchers new to the field of aging on August 23-25.

### **Discussion**

- The Food and Drug Administration (FDA) is working to identify unmet needs for pharmaceutical therapies for AD/ADRD, and to ensure patients have input on clinical trial design and drug development processes.
- The CMS coverage team would like to present updates on coverage determinations of AD/ADRD drugs at the next Council meeting.

- Results of studies on the exposome should inspire development of partnerships to address risk factors.

## **Clinical Care Panel**

**Facilitator:** *Maria Ortega*, DNP, APRN, GNP-BC, PMHNP-BC, CDP, FAANP, FAAN

### ***“Voice of a Person Living with Dementia”***

#### ***Joe Montminy***

Mr. Montminy noticed that his memory seemed to be declining when he was in his early 50s, but his primary care physician reassured him that this was likely due to job stress. After 3 years, his primary care physician referred him to a neurologist, who diagnosed him with younger onset Alzheimer’s disease. She encouraged Mr. Montminy to retire immediately and informed him that his life expectancy was no more than 10 years, with high likelihood that he would no longer recognize his family after 6 years. He was shocked that his life expectancy was so short. Early detection is important. Federal agencies should work to facilitate it. Timely and supportive mental health services are also important for people with dementia. Dementia is financially and emotionally taxing. Income may decrease as expenses increase. Mr. Montminy’s neurologist deals with medical, not emotional, needs resulting from Alzheimer’s disease. It is difficult to find support services. People living with dementia would benefit from learning strategies for managing their emotional needs. Research has shown that suicide risk more than doubles during the 3 months following dementia diagnosis. Risk increases 6.7 times for people younger than 65 years. Earlier detection and diagnosis as well as mental health services would likely reduce this risk.

#### ***Discussion***

- Early diagnosis may be challenging when a patient is very intelligent and competent, as well as when a patient is not neurotypical. Assessment should consider baseline functioning. Diagnostic protocols should be improved to meet the needs of these patients and their families.
- It is important to improve dissemination of information about services available to support people recently diagnosed with dementia.

### ***“Dementia Care Gaps and Recommendations for Improving Clinical Care and Quality of Life for People Living with Dementia and their Care Partners”***

***Krista Harrison, PhD, MPH, and Alissa Bernstein Sideman, PhD, University of California, San Francisco***

Sources of distress for people living with dementia and their caregivers stem from the disease itself, as well as social factors, caregiving, and clinical care and systems. Disease-related stressors include functional impairments and lack of accessible or affordable resources to address impairment. Comorbidities can increase challenges of living with dementia. Prognostic uncertainty makes it difficult for patients and their families to plan for the future. Patients’ loss of independence and privacy are difficult to

deal with. Caregivers may experience loss of freedom and identity. Caregiving is physically, emotionally, and financially challenging. Stigma impairs patients' relationships with family and friends. Disease symptoms and caregiving responsibilities constrain social and professional opportunities. Thwarted expectations of their future are distressing for caregivers, especially spouses. Caregivers experience grief for incremental losses, anticipatory grief, and grief following a loved one's death. Receiving a dementia diagnosis can be extremely stressful, with some patients considering suicide. Patients and caregivers expressed frustration with lack of follow-up care, medication interactions and side effects, and concern that a dementia diagnosis or do not resuscitate order led to poorer quality hospital care.

As many as 66% of patients are not diagnosed during the early stages of the disease. Most dementia care cases are managed by primary care physicians. An advantage to this is that primary care physicians often have long-term trusting relationships with their patients as well as a holistic understanding of their lives and health. Challenges include difficulty differentiating dementia from other conditions, difficulty communicating with specialists, and lack of relevant training. Advantages of specialized memory care include accurate diagnosis and providing support for families in understanding and managing symptoms. Specialists often emphasize diagnosis over prognosis and guidance.

Patients and families report that language and cultural barriers, prioritization of other health issues, and clinician gatekeeping have presented challenges when they have raised concerns about cognitive functioning. Caregivers reported a need to improve approaches for identifying and engaging family, including "family of choice," in addition to needs for more support and resources. Patients and caregivers experienced structural challenges to following up on referrals; confusion about the purpose of referrals; and lack of communication between primary care clinicians, specialists, and families.

Diagnosis can be a relief, as it can result in improved care and support. Patients and families want to learn the patient's prognosis and understand the disease trajectory, especially information specific to their type of dementia. Patients and families also want information about behavioral, safety, and communication issues related to dementia. They want support for planning for the future, especially financial and legal planning, advance care planning, and planning for transitions of care. One study conducted by Dr. Harrison's team found that nearly half of patients in a memory care clinic had not engaged in any advance care planning. With 44% of people with dementia receiving home-based clinical care, there is a need for payment models that support interdisciplinary care at home. Dr. Harrison's team has developed recommendations for anticipatory guidance and a roadmap for clinical care. Improving clinical care will require training and improved administrative processes, resources, and services.

### ***Discussion***

- Studies should prioritize recruitment of diverse participant samples.

## ***“Behavioral Health and Suicide Ideation for People Living with Dementia”***

***Richard McKeon, PhD, MPH, Substance Abuse and Mental Health Services Administration (SAMHSA)***

Older adults in the United States, especially males, are at elevated risk for suicide. Currently, both the federal administration and Congress place high priority on addressing suicide among older adults. Suicide rates among adults aged 65 years and older are notably higher among White people than among people from other racial and ethnic groups. Rates are higher in rural communities than urban or suburban. Older adults are more likely than younger people to die from their first suicide attempt. Firearms are the method used for more than half of suicides in the United States. Immediate access to a firearm during time of crisis is a suicide risk factor for anyone. Prevention efforts should prioritize older rural men. A dementia diagnosis increases suicide risk among younger people. Evidence suggests risk may be highest during the first year following diagnosis, especially the first 3 months. Psychiatric comorbidities increase risk, indicating the importance of screening for depression and suicide risk, particularly at time of diagnosis, as well as the need for behavioral health services, advance care planning, and lethal means safety counseling.

SAMHSA hosts the Suicide Prevention Resource Center, offers senior suicide prevention toolkits, and funds the Zero Suicide grant program. Other federal suicide prevention resources include the 988 Suicide & Crisis Lifeline and the Medicare helpline. All health care settings should offer evidence-based suicide screening, care, and follow-up care, which is the aim of the Zero Suicide grant program.

### ***Discussion***

- Many communities over-rely on police response to suicide risk and attempts, which can exacerbate risk. In addition, many communities over-rely on emergency departments to care for people at risk for suicide.
- Providers should understand potential emotional responses to a dementia diagnosis and associated loss of independence, and they should be aware that these responses may trigger suicidal ideation. In addition, providers should be comfortable discussing suicide and potential triggers.
- Many suicide awareness and information campaigns are youth-oriented. It is important to offer messages about suicide relevant to older adults. SAMHSA is developing such messages based on input from priority populations.

### ***The Alzheimer’s and Dementia Care ECHO Program for Primary Care Clinicians***

***Eric Tangalos, MD, Mayo Clinic***

As the number of older Americans increases, the number of Americans aged 65 years or older who have Alzheimer’s disease is expected to nearly double by the year 2050. The number of geriatricians will have to triple to meet the projected need for care. Currently, about half of primary care physicians report that they do not feel adequately prepared to care for patients with AD/ABD, and more than 25% report that they are sometimes uncomfortable answering questions about AD/ABD. The shortage of care

specialists is more severe in small towns and rural areas than in suburbs and cities. Traditional approaches to continuing medical education can be challenging to participate in, due to time demands, costs, and travel requirements. Virtual platforms help to overcome these challenges. Project ECHO was designed to increase primary care capacity to treat chronic disease by offering case-based interactive learning sessions through video conference with expert mentors. The Alzheimer's and dementia care ECHO was launched in 2018. It offers 12 cohort-based sessions covering 12 core topics, with the purpose of increasing access to timely diagnosis and high-quality care and support. Case study discussions focus on balancing patients' wishes with their care needs. Discussions consider physical exam findings, medical and social histories, decision-making capacity, and financial concerns. Participants learn about cognitive assessment and care planning along with the billing codes for these services. Participants report that the training has been valuable and has improved their practice.

### ***Discussion***

- ECHO offers an opportunity for providers from a broad range of communities, including rural communities, to collaborate and learn from each other about practice and community factors.

## **National Institute of Neurological Disorders and Stroke, 2022 ADRD Summit: Gaps and Opportunities**

### ***Walter Koroshetz, MD***

Participants in the 2022 ADRD Summit discussed and identified research priorities for frontotemporal disorder (FTD), vascular cognitive impairment dementia (VCID), Lewy body dementia (LBD), and mixed etiology dementias, as well as health equity. Research priorities emphasized identifying causes and effective treatment. Participants identified dementia related to previous traumatic brain injuries, limbic-predominant age-related TDP-43 encephalopathy, and COVID-19 as a risk factor for AD/ADRD as research priorities. Key lessons of 2022 sessions included the importance of including people with lived experience in research samples and in research implementation, and the importance of training diverse researchers. Several NIH research projects address equity, through strategies such as studying disparities and recruiting diverse study samples. NIH's Mind Your Risks campaign currently focuses on providing information about risks for cardiovascular disease and associated cognitive impairment among middle-aged Black men. Recent NIH-funded research projects include a study demonstrating that antisense oligonucleotides may be effective in lowering levels of mutant *FUS* proteins, some of which cause amyotrophic lateral sclerosis and FTD; a study of the roles of synuclein and the immune system in neurodegenerative disease; and a study demonstrating that *APOE4* impairs myelination by dysregulating cholesterol in oligodendrocytes.

### ***Discussion***

- Hypertension is the primary risk factor for cardiovascular disease that affects the brain. Cholesterol and atherosclerosis are stroke risk factors, but not a major cause of cognitive impairment.
- It is important for stakeholders, including advocates and policy makers, to learn the results and potential implications of research as soon as possible.

## **Clinical Care Considerations for Disease-Modifying Therapies**

### ***Cindy Carlsson, Chair***

In April 2022, CMS released a national coverage determination (NCD) for aducanumab and future monoclonal antibodies targeting amyloid plaque. In January 2023, the FDA approved lecanemab and CMS confirmed this existing NCD. Clinical care considerations include the current and emerging clinical landscape; diagnostic challenges; access, use, and interpretation of biomarkers; screening with appropriate considerations; therapeutic delivery; safety monitoring; and health equity. New therapies are changing the clinical landscape. Patients and families will need to learn about them to make informed decisions about their care. Clinicians will need training and infrastructure to implement guidelines for safe and appropriate use of new therapies. They will need to learn how to interpret biomarkers. Prescribing must consider the populations represented in clinical trials and factors affecting eligibility for therapy, such as whether a patient can have an MRI scan or is taking medications that cannot safely be combined with new medication therapies. Clinicians must work with patients and families to determine whether new therapies are likely to produce meaningful results or help achieve goals for clinical care. Current therapies require biweekly intravenous infusion, which may present challenges related to scheduling and staffing. Implementing current and potential future therapies requires expanding initiatives to improve diagnosis, training primary care providers to use new therapies, continued research on and efforts to improve therapies, guidelines for use, and translating clinical trial results to information that supports patients' decision-making.

### ***Discussion***

- Aducanumab and lecanemab may be contraindicated for patients taking antithrombotic medication.
- Effective management of comorbidities and medications for multiple conditions should be a consideration for treatment of all AD/ADRD cases, not just those considering new pharmaceutical therapies.
- Cognitive impairment may lead to challenges in adhering to recommendations for managing conditions other than dementia. Dementia care specialists should coordinate and communicate with patients' other health care providers so that the entire health care team can support patients and families in managing multiple conditions.
- The Alzheimer's Registry for Treatment and Diagnosis (ALZNET) tracks treatment outcomes with the aim of informing clinical practice. It would be useful to track



barriers and facilitators to access to emerging therapies through ALZNET or similar resources.

- The Council should work proactively and continuously to ensure equitable access to emerging treatments for AD/ADRD.

## **Social Determinants of Health and Risk Reduction Panel**

**Facilitator:** Joanne Pike

### ***“Social Determinants of Health and Risk Reduction: New Approach to Long-standing Challenges”***

***Amy J.H. Kind, MD, PhD, University of Wisconsin***

SDOH are conditions in the environment where a person lives that influence health and well-being. Categories include education, income, housing, the health system, and social support. SDOH exist on multiple levels, including individual, neighborhood, and community. SDOH are core components of the exposome. The Area Deprivation Index (ADI) measures the social exposome. NIH shares measures and data through the Neighborhood Atlas data democratization tool so stakeholders can use the data to support change. There is extensive evidence that a broad range of SDOH, such as residing in a disadvantaged neighborhood, affect brain health. Targeted interventions can address SDOH, but only with consistent investment of resources, particularly when the aim is to achieve population-level improvements. Sources of support include government, non-profit organizations, and industry. Motivations for investing in efforts to address SDOH include legal requirements, politics, mission, and market forces. Changing market forces requires creating economic incentives.

Typical efforts to address SDOH place the burden of seeking and requesting services on the individual. The exposome approach measures need for all communities, places burden of change on systems, and incentivizes coordination to improve access and outcomes. One example is CMS’s Accountable Care Organization Realizing Equity, Access, and Community Health (ACO-REACH) program, which aims to bring benefits of accountable care to underserved communities through innovative payment plans.

### ***Discussion***

- ADI data have been used to demonstrate need for funding and to inform efforts to recruit diverse research samples.

### ***“From Data to Action in Alzheimer’s Disease Risk Reduction”***

***Karen Hacker, MD, MPH, National Center for Chronic Disease Prevention and Health Promotion, CDC***

CDC prioritizes making progress toward health equity through collective action to address SDOH. Priority areas include food security, tobacco-free policies, built environment, social connectedness, and community-clinical linkages. Racial and Ethnic Approaches to Community Health (REACH) grantees focus on priority determinants of

health through community-based multi-sector partnerships. Partners are essential for providing necessary services that are outside the scope of medical care. Several CDC initiatives and funding programs, including BOLD, aim to improve brain health through addressing SDOH.

### ***Discussion***

- It is critical to develop authentic community partnerships, rather than offer interventions designed and led by people outside the community and implemented without community input.
- Successful efforts at systems change require detailed, feasible plans.

### ***“Racism as a Social Determinant that Affects Brain Health”***

***Lisa Barnes, PhD, Rush University***

Race is a social construct that has led to and perpetuated racism and its associated health disparities, including life expectancy, physical and mental health status, and prevalence of health conditions. Social inequities cause health inequities. Racism is the root cause of racial inequities. Racism operates at several levels, from the intrapersonal to the systemic. Racism is a stressor that affects a broad range of health outcomes, including brain health. Brain health research has tended to emphasize intrapersonal and interpersonal influences on brain health. Events such as the COVID-19 pandemic and murder of George Floyd have increased awareness of the influences of institutional, community, and systemic factors on health. As a result of systemic racism, many people of color believe medical research is biased against them; many believe a cure for Alzheimer’s disease will not be shared equitably across all racial and ethnic groups. People of color, who are at elevated risk for Alzheimer’s disease, are underrepresented in research samples and among researchers. Approaches to addressing structural racism include interventions to increase individuals’ resilience, efforts to alter the environment, and relocating people from high-risk environments. Strategies for improving health equity include policy change, resource distribution, modifying barriers, increasing access to opportunities, integrating measures of inequity into health research, understanding how racism affects health, and empowering communities to create change. Systemic change is necessary to prevent racism from affecting health. Researchers should acknowledge and document the consequences of racism. Measures of racism should assess multiple forms, sectors, and interactions. Researchers and research participants should be diverse.

### ***Discussion***

- Health disparities result from social factors such as access to health care, health literacy, and health care providers’ biases.

### ***“Place: Built and Natural Environment”***

***Ganesh Babulal, PhD, OTD, MSCI, MOT, Washington University in St. Louis***

The environment a person lives in is related to brain health. Neighborhood physical disorder and lack of cohesion are linked to poorer cognitive performance among older

residents. Subjective perception affects cognitive outcomes more than objective measures. System-level change efforts should aim to increase access, affordability, and awareness of resources necessary for good health. Minoritized groups are disproportionately impacted by environmental hazards. Dr. Babulal's research team uses a community-based system dynamics approach. They ask community members about their experiences and concerns in order to build models of systems related to priority concerns, then analyze effects of potential changes. Several policies are likely to improve brain health: prioritizing early childhood education, increasing amount of and access to green space, investing in deprived neighborhoods, limiting use of pollutants, and supporting agencies that serve to protect the environment.

### ***Discussion***

- It is very difficult to change built environments. Change occurs incrementally. It requires investment in communities.
- Climate change has caused environmental health risks and disparities.
- Stakeholders must learn and train others how to implement systems change.

### ***Panel Discussion***

- Change will require sustained investment in underserved communities and community partnerships.
- Investment in literacy, especially early childhood literacy, is crucial for reducing dementia risk.
- Risk reduction efforts should focus on systems-level change rather than individual-level change.
- Financial incentives for change are likely to be effective.

## **Public Comments**

- **Laura Cohen** of Eli Lilly Company advocated for timely and equitable access to therapies targeting amyloid plaques. She said that the CMS decision to restrict access will impede efforts to treat Alzheimer's disease and reduce prevalence. She urged reconsideration.
- **Michael Ellenbogen** said that it is important to provide professional emotional health support services for patients recently diagnosed with dementia. He also advocated for law enforcement programs to support removal of firearms from patients at risk for suicide. He encouraged implementation of policies that allow people with dementia to make choices that reduce end-of-life suffering.
- **Matthew Estrade**, Founder of Catholic Aging, said the agency offers support groups and materials for people with dementia.
- **Ann Lam** of the Physicians Committee for Responsible Medicine supported use of cell cultures and human tissue models in AD/ABR research, as well as efforts to

understand the relationships between biological and social factors affecting AD/ADRD risk and disease progression.

- **Jadene Ransdell**, mother of a 48-year-old man with Down syndrome who has been incorrectly diagnosed with Alzheimer's disease, emphasized the importance of correct diagnosis in this population, and noted that there is a shortage of clinicians with the specialized knowledge necessary to assess patients with Down syndrome. She asked the Council to collaborate with partners to support creation of tools to diagnose AD/ADRD among people with Down syndrome.
- **Matthew Sharp** of the Association for Frontotemporal Degeneration emphasized the importance of early and accurate diagnosis of FTD for clinical care and advance care planning. On average, FTD diagnosis takes 3.5 years.
- **Jim Taylor**, President and Chief Executive Officer of Voices of Alzheimer's, expressed concern about lack of access to new disease-modifying therapies for dementia, saying that CMS is blocking access in order to control costs.
- **Mike Zuendel**, a 68-year-old man diagnosed with mild cognitive impairment due to Alzheimer's disease, has been taking aducanumab for 17 months. Amyloid plaques in his brain have reduced significantly. His cognition has improved. He has not experienced harmful side effects. He encouraged fewer restrictions on access to the drug.

## Concluding Remarks

Dr. Lamont noted that the Council's next meeting will likely be held in early May 2023.

The meeting adjourned at 4:32 p.m EST.

Minutes submitted by Helen Lamont (ASPE).

All presentation handouts are available at <https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-advisory-council/napa-advisory-council-meetings>.