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

Public Comments from Advisory Council Meeting, April 2026

List of Comments

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

PLEASE NOTE: The Public Comments included here are not an endorsement of the views or information by National Alzheimer's Project Act, its Advisory Council members, the Administration or the federal agencies involved in this project.

S. Sivakumaran | 04-20-2026

Sudhir Sivakumaran, CSO, LBDA:

Thank you for the opportunity to provide input.

I would like to begin by acknowledging the importance and impact of the National Alzheimer's Project Act (NAPA) in advancing Alzheimer's disease research, care, and awareness. The progress achieved over the past decade—including advances in biomarkers, diagnostics, and emerging therapies—reflects the strength of this national commitment and has meaningfully advanced the field.

At the same time, the scientific understanding of dementia has evolved in important ways that have implications for how we think about strategy moving forward.

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1. The Field Has Evolved—The Strategy Must Follow

Over the past decade, there has been substantial progress in Alzheimer's disease, including advances in biomarkers, earlier detection, and the emergence of disease-modifying therapies. However, this progress has also revealed a critical reality:

Dementia is not a single disease. It is a biologically complex, multi-etiology condition in which mixed pathology is highly prevalent. Analyses from ADRC datasets suggest that only a small proportion of individuals present with "pure" Alzheimer's disease.

This is particularly evident in Lewy body dementia (LBD), where co-pathology with

Alzheimer's disease is common and directly influences disease progression, clinical presentation, and treatment response.

Yet, much of the current national strategy remains structured around individual diseases, rather than fully reflecting the underlying biological complexity and overlap across neurodegenerative conditions.

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2. Lewy Body Dementia as a Case Study in System Gaps

LBD highlights several systemic challenges that are broadly relevant across neurodegenerative diseases:

a. Misdiagnosis and Delayed Diagnosis

- Patients often go years without an accurate diagnosis
- Symptoms span cognitive, psychiatric, sleep, and motor domains
- Fragmented clinical pathways lead to inconsistent care

From lived experience discussions:

- Symptoms are often attributed to "normal aging" or mischaracterized
- Hallucinations, sleep disturbances, and executive dysfunction are frequently overlooked or misdiagnosed

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b. Fragmented Clinical and Research Infrastructure

- Cognitive, movement, psychiatric, and sleep care pathways often operate independently
- Data is not harmonized across settings
- Trial recruitment and patient identification remain inefficient

Across clinical and research settings:

- Fragmentation across clinic types remains a major barrier
- There is no standardized minimum dataset across sites
- Identifying and stratifying patients for trials remains challenging

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c. Data and Trial Readiness Gaps

- Limited longitudinal, harmonized datasets
- Insufficient granularity for trial design and regulatory needs
- High screen failure rates due to poor characterization

Across stakeholder discussions:

- Data harmonization is critical for addressing key scientific and translational questions
- Co-pathology plays a central role in patient selection, disease staging, and outcome interpretation

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d. Diagnostic and Biomarker Gaps in Real-World Settings

- Advances in biomarkers are not yet fully integrated into routine clinical workflows

- Limited guidance exists on interpretation and return of results
- Primary care settings remain under-equipped to support early and accurate diagnosis

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e. Workforce and Access Challenges

- Limited number of clinicians trained in LBD and related dementias
- Need for stronger engagement of primary care and community-based providers
- Geographic disparities and limited access to specialty care

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3. Core Strategic Gap: Science vs. Implementation

Across research, clinical care, and patient experience, one theme is consistent:

The challenge is no longer discovery—it is translation and implementation.
Despite scientific progress:

- Diagnosis remains inconsistent
- Patients lack access to appropriate care
- Clinical trials continue to face enrollment and efficiency challenges
- Data remains fragmented and underutilized

There is a clear gap between scientific knowledge and real-world implementation.

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4. Expanding the Current Framework to Reflect the Broader Neurodegenerative Landscape

Building on the strong foundation established through NAPA, there is an opportunity to further strengthen national impact by more fully reflecting the broader neurodegenerative disease landscape.

This is not about moving away from Alzheimer's disease. Rather, it is about ensuring that the strategy evolves in step with the science—toward a more integrated, biology-driven approach that accounts for co-pathology, heterogeneity, and real-world patient experience.

Key areas for consideration include:

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1. Incorporate a Broader Neurodegenerative Framework

- Explicitly integrate LBD, FTD, and related dementias within a unified biological context
- Recognize co-pathology as a central feature of disease biology

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2. Prioritize Data Harmonization and Infrastructure

- Support national and cross-disease data integration efforts
- Enable federated and interoperable data systems
- Define minimum datasets to support trial readiness

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3. Accelerate Biomarker and Diagnostic Implementation

- Focus on real-world deployment of biomarkers
- Integrate diagnostic tools into primary care and community settings
- Develop clear guidance for interpretation and return of results

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4. Build Trial-Ready Ecosystems

- Support coordinated, multi-site clinical research infrastructure
- Improve patient identification and referral pathways
- Reduce fragmentation across clinical domains

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5. Address Misdiagnosis and Education Gaps

- Expand clinician education across specialties
- Equip primary care providers with tools for early detection
- Improve public awareness of non-Alzheimer's dementias

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6. Center Patient Experience

- Align diagnostic, care, and research strategies with lived experience
- Improve communication of results and disease understanding
- Ensure access to care is equitable and scalable

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5. Closing Perspective

The field has reached an inflection point.

We now understand:

- The biological complexity of neurodegeneration
- The central role of co-pathology
- The need for integrated, cross-disease approaches

The success of NAPA in Alzheimer's disease has created an opportunity—and a responsibility—to extend that impact across the broader neurodegenerative disease landscape.

If NAPA is to remain maximally impactful, the strategy should continue to evolve toward a systems-level, biology-driven framework that reflects how these diseases actually present, progress, and are treated.

The opportunity is clear.

The science is ready.

The patients cannot wait.

D. Meier | 04-27-2026

Hi my name is Dashiell Meier. I am a filmmaker, college student, actor, and disability rights advocate. I also have Trisomy 21/Down syndrome. I am a National Down Syndrome Society DS-Ambassador and a member of the Stanford University Alzheimer's/Down Syndrome workgroup and advocate for Down syndrome rights.

I want to thank everyone for considering including Down syndrome in the policies about Alzheimer's because this disease is very concerning for people like me and our families. People with Down syndrome have a 90% chance of getting Alzheimer's in our lifetime. It is the number one cause of death for us and we get it earlier than typical people.

I have been working closely with the Stanford Alzheimer's Down syndrome workgroup. In the workgroup we look at data and talk about articles. I would love to help find a way to prevent Alzheimer's from entering the brains of people with Down syndrome and anyone else.

I have also learned from the National Down Syndrome Society that it is really important to include people with Down syndrome in Alzheimer's research because we have three copies of chromosome 21. Studies have found that chromosome 21 carries the amyloid precursor protein gene so we get the plaques in our brains.

People with Down syndrome should be included in research and policymaking because our lives are important and studying and helping us can help everyone. We can all have better health and live longer and have great lives together. Thank you.

K. Fargo | 04-28-2026

Good afternoon. My name is Keith Fargo, and I am director of scientific initiatives at the Lewy Body Dementia Association. LBDA is the nation's leading organization dedicated to Lewy body dementia, or LBD, the second most common form of neurodegenerative dementia. LBD encompasses both dementia with Lewy bodies and Parkinson's disease dementia, affecting approximately 1.4 million Americans.

I want to begin by thanking this council for its sustained commitment to the field. The approval of disease-modifying therapies for Alzheimer's represents a historic achievement — one that this council helped make possible through years of coordination and policy leadership. We celebrate this progress with you and with all Americans affected by dementia.

We also want to acknowledge the council's growing attention to co-pathology and multi-etiology dementia. This is crucially important work. The overwhelming majority of people living with dementia carry more than one pathology, and LBD — which involves alpha-synuclein, tau, and often amyloid — sits at the very center of that complexity.

But that complexity is also an opportunity. Research into LBD holds promise not only for those living with Lewy body dementia, but for the millions more living with Alzheimer's disease and Parkinson's disease. LBDA's Research Centers of Excellence — a network of 27 sites at major medical institutions — overlaps with both Alzheimer's Disease Research Centers and sites participating in the Parkinson's Progression Markers Initiative, reflecting exactly the kind of cross-disease collaboration this council has championed. We are further encouraged that donanemab is now being studied in a clinical trial in LBD.

We urge the council to continue prioritizing research into new diagnostics and therapeutics for multi-etiology dementia. LBDA commits to continuing our partnership with you in that critical effort. Thank you.

All my best,

Keith

L. Reynolds | 04-29-2026

Good afternoon and thank you for the opportunity to speak.

My name is Laurie Reynolds. I'm here today as a caregiver—but also as a sister.

I come from a large family—six siblings in all, three brothers and three sisters—and we all love each other fiercely. Two of my brothers, in particular, are why I'm here today. One of my brothers, Carlo, is a past Board Chair of the National Down Syndrome Society. My other brother, Joe, has Down syndrome.

If you know anything about Down syndrome, you know this isn't unusual. People like Joe face a much higher risk of Alzheimer's, often decades earlier than the general population. And yet, too often, the systems meant to support people with dementia are not built with them in mind.

I am Joe's primary caregiver. I'm doing everything I can. I've been able to hire help who comes for a few hours each day—but I know I'm one of the lucky ones.

Because finding that help wasn't easy.

Most caregivers and home health aides have little to no experience supporting people with Down syndrome. There's no built-in training, no standard preparation. You have to find someone who is willing to learn—and that takes time, energy, and resources that families are already stretched thin trying to provide.

And even when care needs increase, families face another barrier: many long-term care and memory care facilities are simply not prepared—or willing—to support individuals with Down syndrome because of their unique needs.

So families like mine are left asking: where do we go?

I carry this every day. I am exhausted. I am worried. And I am heartbroken watching my

brother slowly change.

This is what long-term care really looks like for families: not just logistics, but love stretched to its limits.

That's why I'm here to ask you to ensure that long-term services and supports are truly inclusive of people with Down syndrome.

Inclusion means recognizing different needs—not ignoring them.

It means training providers who understand both intellectual disability and dementia.

It means making sure people like Joe are welcomed—not turned away—when they need higher levels of care.

And it means ensuring families can access support before they reach a breaking point. Because right now, too many families are navigating this alone, in systems that were never designed for them.

Joe deserves better.

Families like mine deserve better.

Please make inclusion a priority—not an afterthought—in the National Alzheimer's Plan.

Thank you.

R. Eppes | 05-01-2026

The International Association for Indigenous Aging (IA2) is a part of the CDC Healthy Brain Initiative. Our team has helped American Indian and Alaskan Native communities build brain health awareness, focusing on their Elders. These communities are truly the First Americans. I am proud to say that progress has been made. For these First Americans, there is now a Roadmap for public health agencies to use to support discussion about dementia and caregiving as Captain Loustalot with CDC mentioned earlier. There are Healthy Food, Healthy Brain rack cards, flyers describing how to reduce your risks of getting dementia, videos like "The River Story" that describes the journey that is travelled, Dr. Ling mentioned the 4Ms, we have adaptated the 4Ms Framework for Age Friendly Healthcare that is being adopted by communities across the country and many other materials to guide Elders in protecting their brains, including one of my favorites, the Dementia Bingo game. I wish we had time to play a round of that right now. Perhaps best of all, there are real conversations taking place among health professionals, Elders and families in these Corporations, Pueblos, Tribes and Nations. This work helps to fulfil the legal treaty obligations of the United States to these communities.

And there is more work to be done. There are 575 Federally Recognized Tribes in the United States. In addition, there are many people from tribes that have not reached the status of Federal recognition, including the Native Hawaiians. Reaching and serving all of these populations, recognized or not, can be challenging because of physical geography, language and cultural differences.

These past 5 plus years have shown that focusing efforts to create materials and strategies for these tribal communities is effective. The Elders in the communities touched by the Healthy Brain Initiative are aware of and practicing the actions that can reduce risks and build healthier habits. Families and communities are beginning to understand caregiving strategies.

As I look at the flags of some of these communities in this very room, it reminds me that this work is showing positive results and it would be a mistake, in my opinion, to fail to continue it. I ask the members of this Advisory Board to use your influence to continue the work for our First Americans.