

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

SUMMARY OF MEETING

August 03, 2026

The Advisory Council on Alzheimer's Research, Care, and Services held its third meeting of the year at 10:00 a.m. Eastern Daylight Time in Washington, DC, and virtually. Dr. Maria-Theresa Okafor, Designated Federal Officer, called the meeting to order. Michelle Branham, Advisory Council Chair, welcomed meeting attendees and reviewed the meeting agenda. The meeting was open to the public.

Advisory Council Members Present

- *Non-Federal Members:* Michelle Branham (Chair); Kathryn Newkirk (Vice-Chair); Randall Bateman; John D. Couris; Samuel Giles; Ricardo A. Hanel; James S. Hartsell; Michael Mayo; Kristi Putnam; Gina Waterhouse; Steve Waterhouse; Jonathan Weiss
- *Federal Members:* Erin Long, Administration for Community Living (ACL); Kevin Chaney, Agency for Healthcare Research and Quality (AHRQ); Helen Lamont, Office of the Assistant Secretary for Planning and Evaluation (ASPE); Maria-Theresa Okafor (ASPE); Fleetwood Loustalot, Centers for Disease Control and Prevention (CDC); Shari Ling, Centers for Medicare & Medicaid Services (CMS); Dwayne Taliaferro, Department of War (DOW); Michael Butkovich, Federal Emergency Management Agency (FEMA); Teresa Buracchio, Food and Drug Administration (FDA); Joan Weiss, Health Resources and Services Administration (HRSA); Jolie Crowder, Indian Health Service (IHS); Richard J. Hodes, National Institute on Aging (NIA); Robert Weathers, Social Security Administration (SSA)
- *Quorum present?* Yes
- *Advisory Council Designated Federal Officer:* Maria-Theresa Okafor (ASPE)

Other Federal Representatives Present: Mary Lazare (ACL); David Kashihara (AHRQ); Kim Wittenberg (AHRQ); Cynthia Goss (ASPE); Romeo Galang (CDC); Sarah Irie, Centers for Medicare and Medicaid Innovation (CMMI); Lenise Cummings-Vaughn (CMS); Tara McMullen (CMS); LaShonda Mui (FEMA); Jennifer Solomon (HRSA); Valerie Jones (IHS); Jill Beaver, NIA; Brian Gray (NIA); Kenneth Santora (NIA); Amy Bany Adams, National Institute of Neurological Disorders and Stroke (NINDS); Frank Shewmaker (NINDS); Alynda Wood

(NINDS); Michael Goldstein (SSA); Meghan Reeves (SSA); Antoinette Shappell, Veterans Administration (VA)

General Proceedings

For detailed information, please visit the [August 03, 2026 Advisory Council](#) presentation slides and handouts.

RESEARCH SUBCOMMITTEE PRESENTATIONS

Opening Remarks – Research Subcommittee Chair

Dr. Randall Bateman

- Alzheimer’s research is advancing rapidly, with significant progress since 2023, including new FDA-approved blood-based diagnostic tests, longer-term data on treatments and outcomes, and growing potential for earlier diagnosis, treatment, and prevention.
- Significant research gaps remain, including the identification of biomarkers, research involving people living with Down syndrome, and strategies to prevent late-onset Alzheimer’s disease. Alzheimer’s research funding is currently equivalent to less than 1 percent of the disease’s annual economic cost. Greater investment, combined with emerging artificial intelligence (AI) capabilities, could accelerate progress.

“Biomarkers”

Dr. Lawren VandeVrede, University of California San Francisco

- Alzheimer’s disease is defined by the presence of specific brain proteins, including amyloid plaques and tau tangles. Biomarkers can inform the diagnosis, staging, treatment, and prognosis of Alzheimer’s disease.
- Compared with PET scans and lumbar punctures, blood biomarkers represent a major advancement in accessibility and scalability. Tests such as p-tau217 offer high diagnostic accuracy and could expand Alzheimer’s testing to routine primary care. However, challenges remain, including unclear reimbursement, variable test performance, and the impact of certain health conditions on test results.

“The Convergence of Down Syndrome and Alzheimer’s Disease — Scientific and Ethical Imperatives”

Dr. Michael S. Rafii, University of Southern California

- People living with Down syndrome face a 95 percent lifetime risk of dementia, with symptoms typically emerging around age 55. The extra copy of chromosome 21 leads to overproduction of amyloid precursor protein (APP), resulting in a genetic form of Alzheimer's disease strongly driven by APP.
- In people living with Down syndrome, amyloid accumulation begins to accelerate around age 35, approximately 20 years before symptoms typically emerge. Alzheimer's disease follows a similar biological course similar to that seen in the general population.
- The Alzheimer's Clinical Trials Consortium conducts trials that include people living with Down syndrome. Current trials are evaluating the safety and effectiveness of immunotherapies that target amyloid and APP production.
- The Down Syndrome Research Partnership Board engages people living with Down syndrome and their families as research partners and incorporates their feedback into study protocols.

“Can We Detect and Treat Alzheimer's Disease a Decade Before Dementia? (And Why We Must!)”

Dr. Reisa Sperling, Harvard Medical School

- Over the past 50 years, researchers have improved the ability to identify people with Alzheimer's disease pathology and found that treatment earlier in the disease process is associated with better outcomes.
- Lecanemab, one of two FDA-approved treatments for Alzheimer's, slowed disease progression by 27 percent. Among research participants who began treatment with lower levels of pathology, the treatment effect was nearly twice as large.
- Secondary prevention trials are testing anti-amyloid treatments and combinations of treatments targeting amyloid and tau in people who have evidence of amyloid or tau pathology but have not yet developed cognitive impairment.
- Earlier detection may help identify people at risk of cognitive impairment or dementia and inform decisions about who may benefit from treatment, which treatment may be appropriate, and when treatment should begin.

“AI and Alzheimer's Disease”

Dr. Wendy Nilsen, National Science Foundation

- AI can bring together multi-modal data to explore disease trajectories, potential targets, and assess outcomes; rapidly generate predictive models using large amounts of data, analyze existing data and research to generate new hypotheses for Alzheimer's research; automate aspects of research processes; and generate data.

- AI can also create tailored experiences for patients by learning their preferences over time and supporting caregivers by synthesizing resources, identifying behavioral patterns, and monitoring for safety concerns.
- The National Artificial Intelligence Research Resource aims to accelerate AI-powered discovery and innovation, expand the AI research and development workforce, increase access to and use of public and commercial AI resources, and strengthen public trust in AI.

“Consortium for Biomedical Research and Artificial Intelligence in Neurodegeneration (C-brAIIn) AI-Powered Discovery & Potential Applications”

Dr. Randall Bateman

- C-brAIIn aims to use AI to deepen understanding of Alzheimer’s disease at the molecular level and accelerate discoveries in Alzheimer’s and other neurodegeneration diseases.
- C-brAIIn has released three open-source AI tools that allow researchers to analyze their own data in about one hour—analyses that could take months to complete manually.
- C-brAIIn is launching an initiative to integrate decades of research data to model individual disease progression and identify molecular drivers that may contribute to that progression.

Discussion

- The Advisory Council discussed the use of AI in patient care, noting that AI is expected to augment rather than replace direct patient care. AI could help physicians make more efficient use of limited time with patients, for example, by collecting and summarizing information before appointments. Presenters and Advisory Council members emphasized the importance of clinical guidelines, patient trust, and ensuring that sensitive information, such as diagnoses, is communicated by a human.
- The Advisory Council expressed interest in therapies targeting both amyloid and tau tangles, as well as research into why some people with Alzheimer’s biomarkers do not experience symptom progression.
- Presenters noted that blood biomarker testing is not currently recommended for people without Alzheimer’s symptoms. However, recommendations could change if secondary prevention trials demonstrate effectiveness and the therapies evaluated in those trials become available.

FEDERAL PROGRESS

Federal Agency Updates

ASPE – Maria-Theresa Okafor

- ASPE updates the [National Plan to Address Alzheimer's Disease](#) annually. In July, ASPE hosted five listening sessions with caregivers, people living with Alzheimer's, advocacy groups, and researchers.
- ASPE has an open [Request for Information](#) (RFI) seeking public input on successes, opportunities for improvement, and other considerations for updating the National Plan.

CDC – Fleetwood Loustalot

- The Building Our Largest Dementia (BOLD) Infrastructure Cooperative Agreement supports 43 state, tribal, local and territorial health departments in implementing strategic plans. Recipients recently convened to share success stories and network.
- CDC is reviewing applications for the National Healthy Brain Initiative (HBI) Combined Notice of Funding Opportunity (NOFO) and expects to issue awards later this summer.
- The 2026 Behavioral Risk Factor Surveillance System is currently in the field and includes questions on cognitive decline and caregiving trends in select states.

CMS – Shari Ling

- As part of the proposed 2027 Proposed Physician Fee Schedule, CMS released an RFI on intensive lifestyle interventions to slow progression of Alzheimer's disease. CMS is [seeking comments](#), which are due September 14, 2026.
- Age-friendly attestation in the Hospital inpatient Quality Reporting Program promotes evaluation of cognition in acute care settings, including attention to mentation, delirium detection, screening, assessment, and management.
- CMS is introducing a new Risk-Based Survey process designed to improve efficiency and effectiveness of nursing home oversight.
- CMS reported an increase in the number of partners participating in the GUIDE (Guiding an Improved Dementia Experience) Model, which aims to improve the quality of dementia care and reduce associated costs.

FEMA – Michael Butkovich

- FEMA's Alzheimer's Task Force works to integrate the needs of individuals living with Alzheimer's and other dementias across FEMA operations, including preparedness,

response, recovery, and mitigation, as well as training for state, local, tribal, and territorial partners.

HRSA – Joan Weiss

- The Geriatrics Workforce Enhancement Programs (GWEPs) train the health care workforce to provide person-centered, age-friendly care to older adults.

NIA and NINDS - Richard Hodes and Amy Bany Adams

- A recent NIH-funded study estimated that 5.7 million adults age 51 and older in the United States are living with dementia and are supported by 5.2 million care partners. The study estimated that the total cost of dementia will reach \$818 billion this year in the United States.
- U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER), a randomized controlled trial, found that multidomain lifestyle intervention improved cognition among high-risk older adults over two years. An ancillary study found that structured intervention may also enhance cognitive resilience.
- An NIH-funded study identified a new blood biomarker that may help predict onset of Alzheimer's symptoms.
- TDP-43 can accumulate in the cytoplasm of neurons and glia, forming harmful aggregates that impair function. An NIH-funded study found that short RNA chaperones can bind to TDP-43, reduce aggregation, restore nuclear localization and, and improve normal function. These chaperones could potentially be optimized as therapies to restore TDP-43 function and solubility.
- The Advisory Council on Parkinson's Research, Care, and Services was established to coordinate federal efforts, accelerate research, improve care, and strengthen support for people living with Parkinson's and their families. Its next meeting will be held on August 24, 2026. NINDS is also [seeking broad input](#) to inform development of the National Plan to End Parkinson's; comments are due August 22nd, 2026.

FDA - Teresa Buracchio

- On July 16th, FDA approved subcutaneous administration of Lecanemab for initiation of treatment for Alzheimer's disease.

IHS – Jolie Crowder

- IHS released a NOFO to establish national resource centers with two focus areas: caregiver support and tribal epidemiology.

- Over the past four months, IHS has offered over 60 training sessions, reaching more than 500 health care staff.
- IHS plans to release an internal data dashboard on age-friendly care to support quality management and is developing clinical care measures for use in clinical programs and grants.

“The Federal Role in Bringing Breakthrough Treatments to Patients”

Richard Hodes, Teresa Buracchio, and Shari Ling

- NIH funds foundational science and translational and clinical infrastructure and helps reduce risk for subsequent industry-funded research. NIH-funded research contributed to the discovery and validation of Lecanemab and Donanemab. NIH also develops and tests new candidate therapies, studies drug repurposing, and continues to investigate FDA-approved treatments.
- FDA provides advice during product development on the data needed to support the initiation of clinical trials, monitors the safety of clinical trials, and assesses safety in post-marketing settings.
- FDA supports medical product development by drafting guidance for industry, advancing the biologic staging of disease to guide early intervention strategies, conducting regulatory research, participating in public-private partnerships, and engaging with Alzheimer’s disease and related dementias (ADRD) stakeholders.
- CMS is the largest health care payer in the world. CMS can support evidence generation, but its primary role is as a payer.
- Services covered by Medicare generally must be reasonable, necessary, and useful, and fall within a statutorily defined Medicare benefit category.
- In 2022, CMS established coverage for FDA-approved monoclonal antibodies that target amyloid for the treatment of Alzheimer’s disease through a process called Coverage with Evidence Development.

“The ASAP Act”

Rachel Conant, Alzheimer's Association

- Medicare cannot cover screening tests for people who do not have symptoms of Alzheimer’s disease. The ASAP Act would remove this legal barrier, allowing Medicare to cover such screening tests.
- The bill would not mandate coverage or screening, approve specific tests, or set a price.

- The bill has strong bipartisan support and sponsorship in both chambers of Congress and is supported by American voters. Current efforts are focused on advancing the bill through the relevant committees for consideration.

“The BRIDGE Act”

Jim Taylor, Voices of Alzheimer's

- Approximately 200,000 Americans under age 65 are living with young-onset Alzheimer's and face a two-and-a-half-year delay before receiving Social Security Disability Insurance coverage. This delay may limit access to available treatments, which are most effective in the earliest stages of cognitive impairment.
- The Bridging Relief in Delayed Government Enrollment (BRIDGE) for Young Onset Alzheimer's Disease Act of 2025 (HR 6799) would eliminate these waiting periods for people living with young-onset Alzheimer's. The bill has been introduced in the House of Representatives and is expected to be introduced in the Senate in September.

“The CHANGE Act”

Erika Sward, UsAgainstAlzheimer's

- Medicare requires documentation of psychosocial and the ability to complete activities of daily living during annual wellness visits. Cognitive impairment is also assessed but may be evaluated through “direct observation,” potentially resulting in missed opportunities for follow-up and early diagnosis.
- The CHANGE Act (H.R. 3501, S. 1799) would require the use of a validated, NIA-approved cognitive impairment detection tool and documentation of results in patients' medical records.
- The [National Alzheimer's Summit](#) will be held virtually September 16-17, 2026.

INNOVATION IN ALZHEIMER'S DISEASE INTERVENTIONS

“Robotic-Enabled Microsurgical Intervention for Neurodegenerative Disease”

Dr. Ricardo Hanel

- Very early studies conducted in China suggest that a surgical procedure connecting lymphatic vessels to the jugular vein may improve lymphatic drainage and reduce amyloid protein levels. Robotic-enabled microsurgical systems may facilitate the procedure and reduce human error.
- The Robotic-Enabled Microsurgical Intervention for Neurodegenerative Disease (REMIND) study has received FDA approval to proceed. Three patients have

undergone the procedure, and the study has received FDA clearance to enroll and treat 12 additional patients.

- The study is primarily evaluating the safety of the procedure while also measuring biomarkers in blood, via PET scan, and in cerebrospinal fluid.

SUBCOMMITTEE RECOMMENDATIONS

The Research, Clinical Care, Long-Term Services and Supports, and Risk Reduction Subcommittee chairs presented [recommendations](#) to the full Advisory Council. All Advisory Council members received a [handout](#) containing the draft recommendations.

Voting and Adoption of Recommendations

- The non-federal members of the Advisory Council on Alzheimer's Research, Care, and Services voted unanimously to approve the recommendations.

Public Comment

- **Ian Kremer (LEAD Coalition)** called for legal protections against discrimination for asymptomatic individuals with genetic markers or pathology before diagnosis or treatment. Kremer also recommended greater involvement of FEMA and the VA in preparedness, diagnosis, treatment, and connections to nonclinical supports.
- **Matt Sharp (Association for Frontotemporal Degeneration)** called for frontotemporal degeneration to be explicitly named in the National Plan, including areas where frontotemporal degeneration diverges from Alzheimer's disease. Sharp identified priorities including biomarkers and diagnostic tools, genetic counseling, care models, caregiver education and support, and home- and community-based services for people with complex behavioral needs.
- **Dr. Sudhir Sivakumaran (Lewy Body Dementia Association)** called for greater visibility of Lewy body dementia in the National Plan, including specific, measurable priorities, support for biomarkers and data infrastructure, and involvement of people living with Lewy body dementia and their caregivers in research planning.
- **Scott Frey (Alliance for Aging Research)** raised concerns that the current measure for prescribing antipsychotic medication equates lower prescribing rates with higher-quality care. Frey urged CMS to retire the current measure and better distinguish clinically appropriate prescribing from misuse.
- **Dee Stufflebam (Caregiver)** shared the experience of their 38-year-old daughter, Susie, who is living with Down syndrome and an enthusiastic participant in Alzheimer's research. Stufflebam noted the deaths of Susie's friends from Alzheimer's disease, encouraged continued efforts to identify treatments, and called for the inclusion of people living with Down syndrome in clinical trials.

- **Margot Rhondeau (for Kate O'Neill, National Down Syndrome Society)** called for inclusion of the Down syndrome community in the National Plan and access to emerging and existing Alzheimer's disease diagnostics. Rhondeau highlighted efforts to support the inclusion of people living with Down syndrome in research studies and recommended representation from the Down syndrome community on the Council.
- **Dawn O'Gara (Association for Frontotemporal Degeneration ambassador)** shared the experience of O'Gara's father, who received a frontotemporal dementia diagnosis before age 65 and faced limited eligibility for resources and access to care because he did not have an Alzheimer's disease diagnosis. O'Gara highlighted the significant financial burden associated with young-onset dementia and called for a national strategy encompassing all types of dementia.
- **Dawn Kirby (Association for Frontotemporal Degeneration)** shared the experience of their daughter, who received a frontotemporal dementia diagnosis at age 29 after difficulty obtaining an accurate diagnosis. Kirby emphasized the substantial financial and emotional burden on families and noted that rare conditions remain significant. Kirby also described young people who received frontotemporal degeneration diagnoses after earlier psychiatric misdiagnoses.
- **Julia Wood (Lewy Body Dementia Association)** raised concerns about severe adverse effects of high-potency antipsychotic medications among people with Lewy body dementia. Wood urged the Council to recognize haloperidol exposure as a national safety priority and called for emergency department and hospital protocols, long-term care training, electronic health record alerts, and inclusion of this issue in care models and quality measures.

Concluding Remarks

- Michelle Branham, Advisory Council Chair, thanked meeting attendees for their participation and adjourned the meeting at 5:00 p.m.