Advisory Council on Alzheimer's Research, Care, and Services

Summer 2024 Meeting

August 2, 2024

U.S. Department of Health and Human Services Materials available at: http://tinyurl.com/NAPAmeetings



OFFICE OF BEHAVIORAL HEALTH, DISABILITY, AND AGING POLICY

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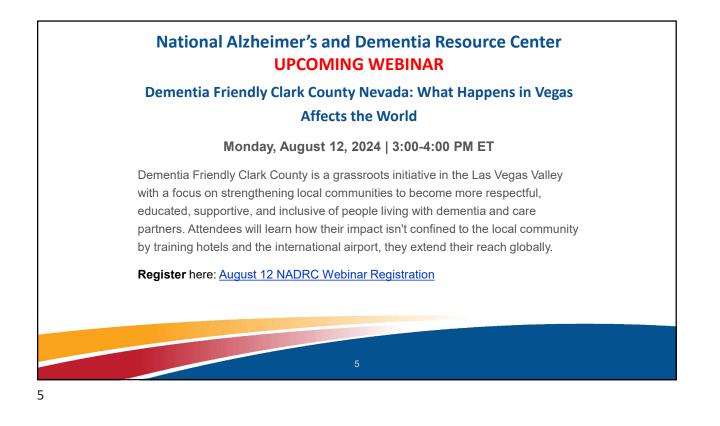
Federal Updates

- Administration for Community Living (ACL)
- Agency for Healthcare Research and Quality (AHRQ)
- Office of the Assistant Secretary for Planning and Evaluation (ASPE)
- Centers for Disease Control and Prevention (CDC)
- Food and Drug Administration (FDA)
- Indian Health Service (IHS)
- National Institutes of Health (NIH)

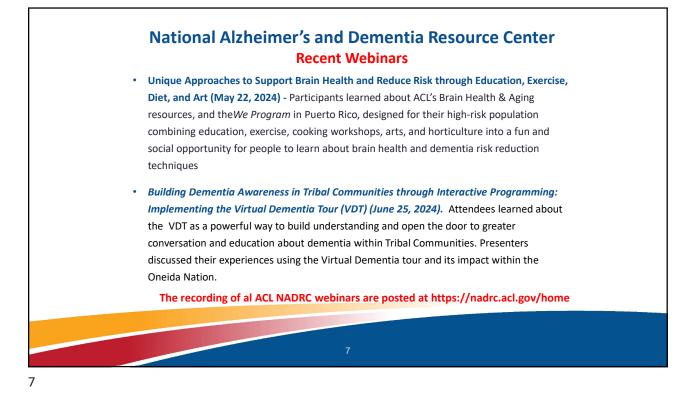


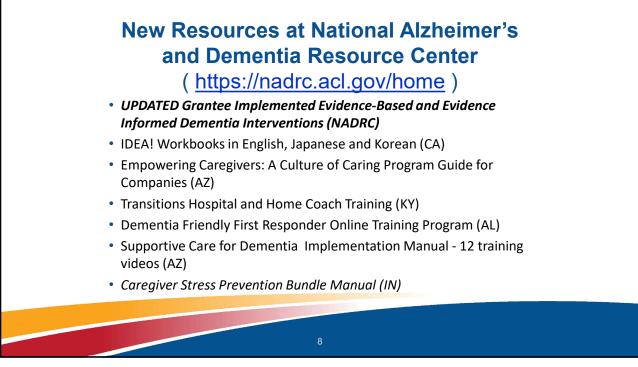




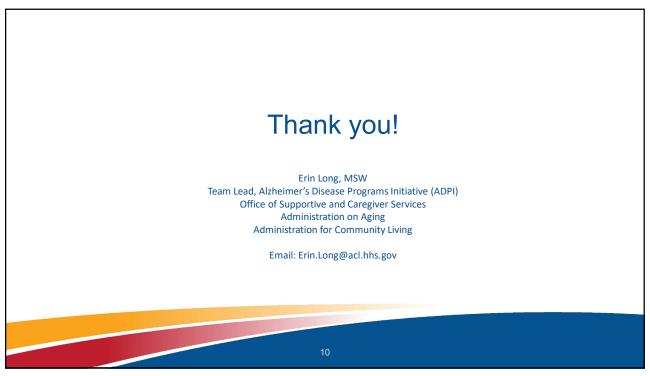






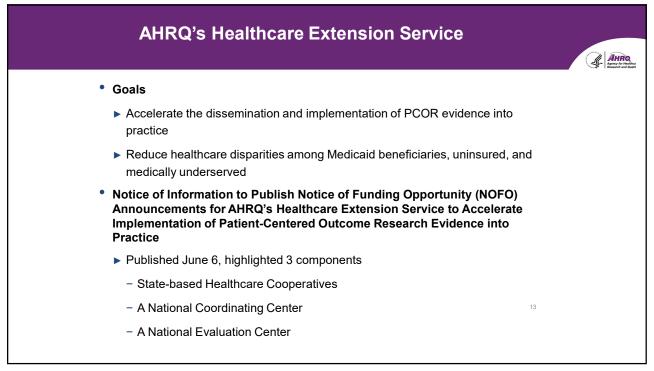


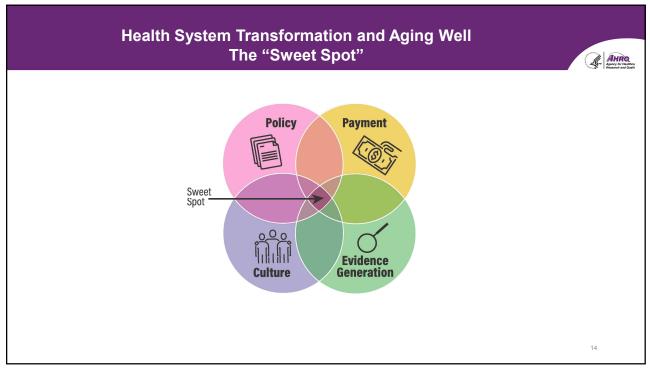


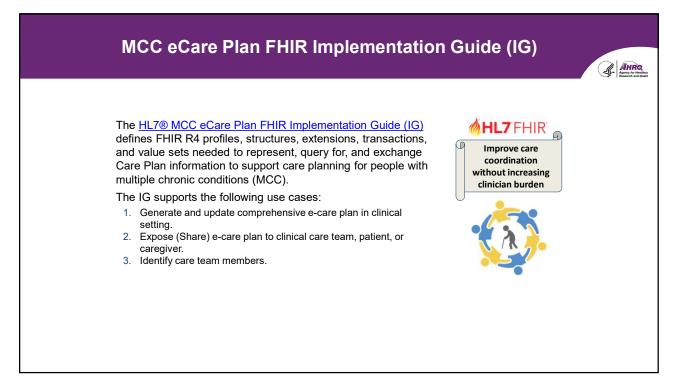






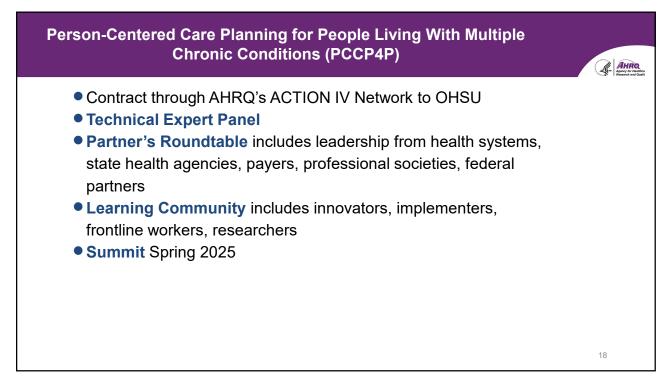








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August 2024 Updates

Helen Lamont, Ph.D. Director, Division of Disability & Aging Policy

U.S. Department of Health and Human Services



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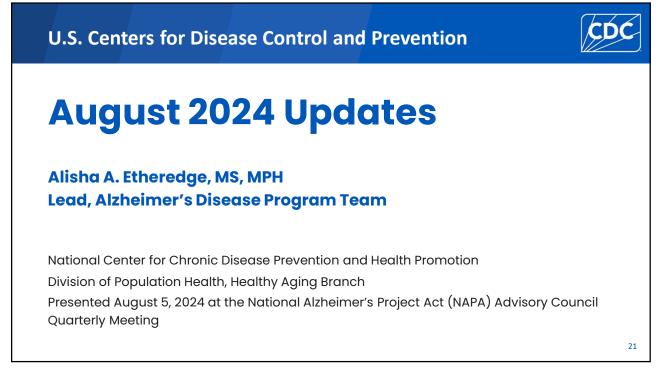
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Recent ASPE Briefs

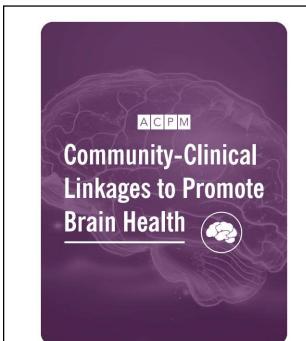
- <u>Changes in Ownership of Skilled Nursing Facilities from 2016 to 2021: Variations by Size, Occupancy Rate, Penalty</u> <u>Amount, and Type of Ownership</u>
 - Examined ownership data and identified facilities more likely to experience ownership changes and varying NH ownership structures and transactions potentially influencing quality of care delivered to vulnerable residents.
 Facilities that were medium-sized, had low occupancy rates, or had incurred more fines, were more likely to experience a change of ownership
- Medicaid Home and Community-Based Services Section 1915(c) Waiver Policy Flexibilities During the COVID-19 Public Health Emergency: State Agency, Provider, and Consumer Experiences
 - Interviewed state agencies and HCBS consumer and provider groups from nine states about their experiences with the selection, implementation, evaluation, and continuation of Appendix K policy flexibilities adopted during the COVID-19 public health emergency (PHE). State agencies relied on prior experiences, feedback from HCBS provider and consumer groups, and priorities around health and safety concerns, and addressing workforce shortages. Some challenges with implementation included uncertainty around duration of flexibilities, accessing and interpreting flexibility guidance, limited state administrative infrastructure, and provider payment uncertainty/delays.



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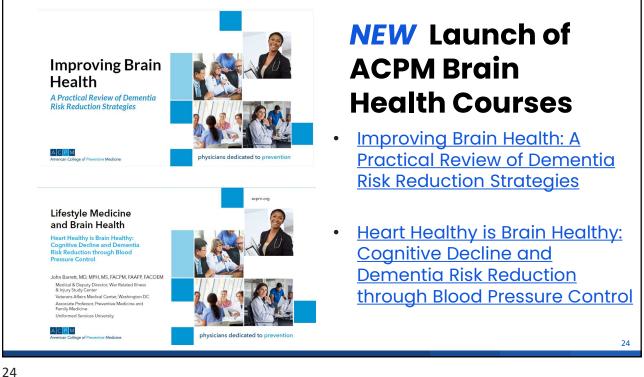


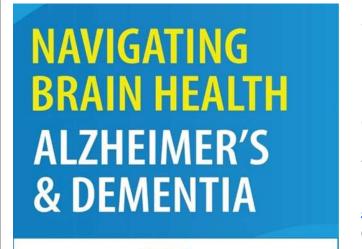


NEW Toolkit: Community-Clinical Linkages to Promote Brain Health

Brain-Health-Kit-v10.cdr (acpm.org)

- Designed for preventive medicine providers to implement and inform their practice around improving brain health within health systems.
- This tool aims to activate preventive medicine physicians and educate patients on ADRD, reduce risk factors related to dementia, and improve the brain health and cognitive functions of populations by leveraging clinical-community linkages through an equity-centered approach.





Webinar Series: Navigating Brain Health with AMA, CDC, and Alzheimer's Association

Access the recordings and claim CME!

AMA

HBI Road Map Strategists: Opportunity for Local Health Departments

RALZHEIMER'S

Applications now open!

- National peer cohort focused on implementing HBI Road Map actions in communities
- Local health departments (LHDs) receives funding, technical assistance, and peer support
- Up to 10 LHDs will be selected for a 9-month program
- Establishes a Road Map Strategist within the LHD, a public health professional focus on building dementia expertise and changing system
- Next cohort launches January 2025

Applications due September 26, 2024

HEALTHYBRAIN INITIATIVE

Application

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Learn more at the Alzheimer's Association <u>Submittable</u> page

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Alzheimer's: A Public Health Issue

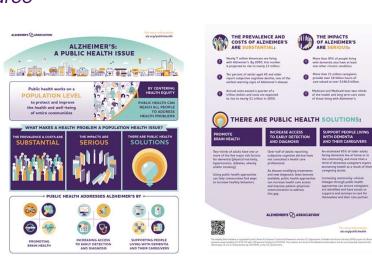
New Infographic Resource

Quick explainer of:

- Public health
- Alzheimer's and dementia as public health issues

Find it at alz.org/publichealth → Public Health and Alzheimer's

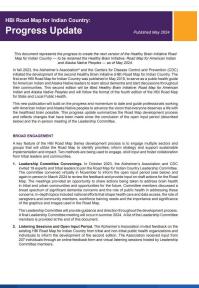
Direct Link Download



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HBI Road Map for American Indian and Alaska Native Peoples Update

- Development of the next edition of the Road Map for Indian Country – renamed the Healthy Brain Initiative: Road Map for American Indian and Alaska Native Peoples – is underway.
- Leadership committee and Federal Liaison review of a full draft is complete
- <u>Progress Update</u> available on the Alzheimer's Association <u>website</u>
- New Road Map will be released in November 2024



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SDOH Resources – 2 more Webinars and Infographics

- Register for the series and share the flyer and opportunity with your health department contacts
- Participants will be able to:
 - Identify the relationship between SDOH and dementia risk.
 - Understand modifiable risk factors and their impact on dementia risk reduction.
 - Learn strategies from State and Local Health Department experts on integrating dementia risk into broader public health agendas.
 - Engage in a discussion during the Q&A portion of the event.
- <u>SDOH Infographics</u> related to dementia risk reduction now available

Register today <u>bit.ly/PHCOEwebinar</u>!



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NEW Risk Factor Videos

- Alzheimer's Association Public Health Center of Excellence on Dementia Risk Reduction recently released new videos on modifiable risk factors for cognitive decline, featuring experts from the Association and Rush Alzheimer's Disease Center.
- Presenters shared scientific evidence on:
 - Diet and Nutrition
 - Cognitive Engagement
 - Mild Traumatic Brain Injury



Watch and share the video series at bit.ly/3U795JK

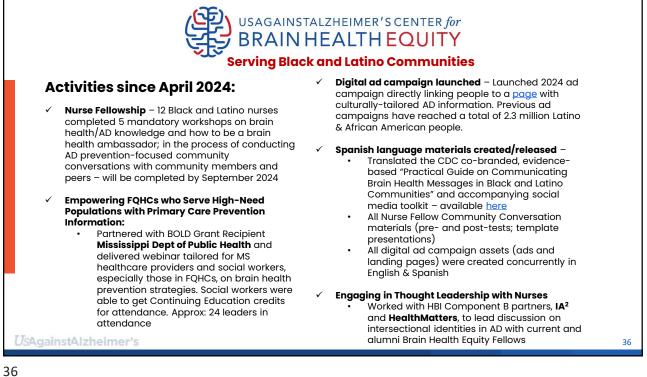






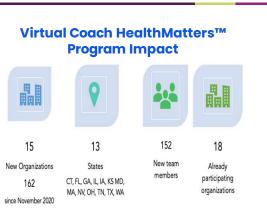






HealthMatters for People with IDD

- Supporting 162 organizations across the U.S. to implement the Virtual HealthMatters Program and provide 6 Pillars of Brain Health among People with IDD and their Supports.
- Developing Fact Sheets for Brain Health and Dementia Care from Listening Circles in collaboration with International Association for Indigenous Aging (IA2)/HealthMatters Program.
- Co-presented with UsAgainstAlzheimer's and IA2 to discuss common cultural values, barriers and facilitators; dispel myths; and provide tools/resources for nurses providing dementia care.
- Provided 6 Pillars for Brain Health: Promoting Health Equity for People with Intellectual and Developmental Disabilities training to Americorp Members working with The Arc US in July.

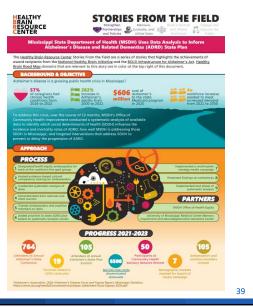


Health Matters[™] Program

© 2023 HealthMatters[™] Program **NTG Updates** on Intellectual Disabi and Dementia Practices NTG funded with Special Olympics Inclusive Health Initiative Project, "Changing Thinking! A National Initiative to Enhance Access to Critical Health Care and Supports for Adults with Intellectual and Developmental Disabilities and Dementia." September 2024 through June 2025. • Implementing CMS Guiding an Improved Dementia Experience (GUIDE) Model to support adults with IDD and their caregivers affected by dementia Incorporate Gerontological Society of America (GSA) 2024 publication, Addressing Brain Health in Adults With Intellectual Disabilities and Developmental Disabilities: A Companion to the KAER Toolkit for Primary Care Providers. The KAER Toolkit provides resources for Kickstarting brain health needs, Assessing cognitive impairment, Evaluating for dementia, and Referring to community resources. Operationalize the 2024 seminal report on autism, dementia, brain health titled "Autism, aging, and dementia: A consensus report of the Autism/Dementia Work Group of the 2nd International Summit on Intellectual Disabilities and Dementia."

NEW Stories from the Field Posted on CDC's HBRC Website

- Healthy Brain Resource Center (HBRC) Stories from the Field are a series of stories that highlight the work of our BOLD and HBI grant recipients
- Newest story highlights the <u>Mississippi BOLD public health</u> <u>program</u> and their work to address social determinants of health that influence the incidence and mortality rates of ADRD



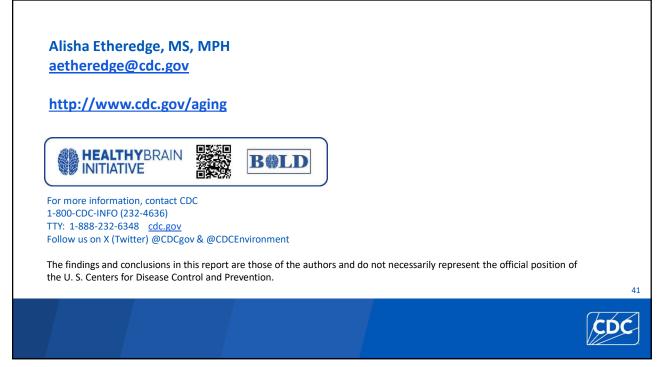
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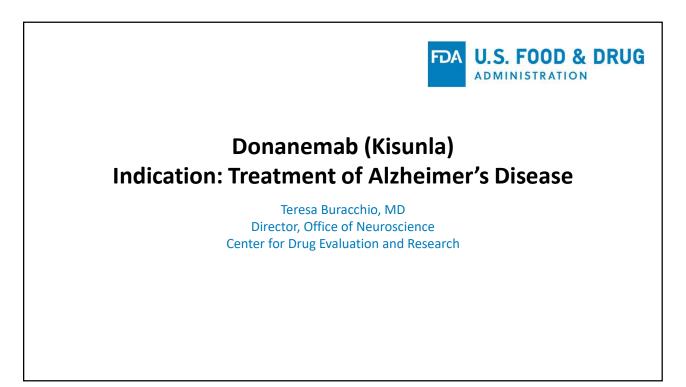
Advancing Dementia Care: Introducing Virginia Dementia Patient Registry

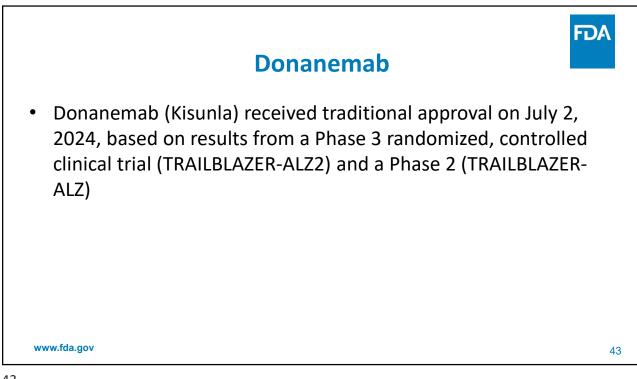


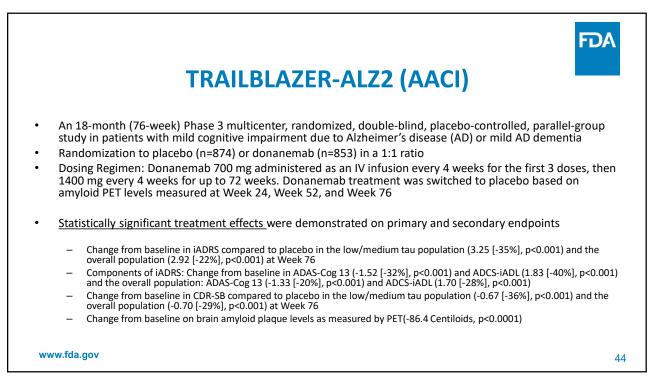
With a pressing need for specialized care and accurate data on dementia prevalence, the <u>Virginia Department of Health (VDH)</u> embarked on a groundbreaking initiative. Supported by CDC funding, VDH awarded four mini-grants to enhance community education, caregiver training, and the development of a state-of-the-art dementia registry: the Virginia Dementia Patient Registry.

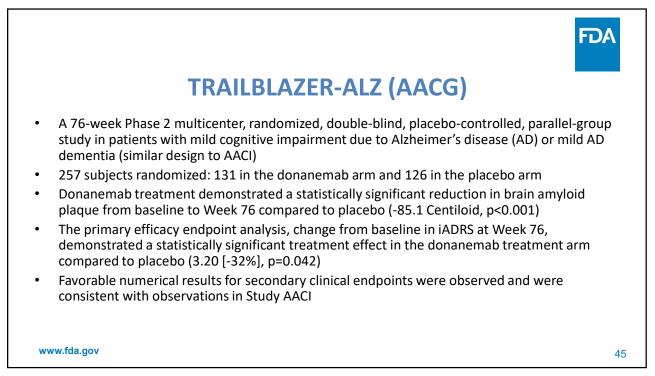
This registry, one of only four in the country, provides valuable insights into dementia prevalence among different groups. By leveraging this information, social and medical services can be tailored to meet the specific needs of individuals living with dementia. These projects are made possible by the "Building Our Largest Dementia Public Health Programs to Address Alzheimer's Disease and Related Dementias" award.

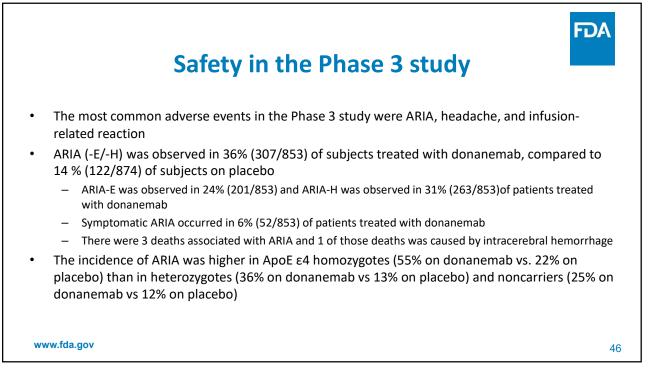


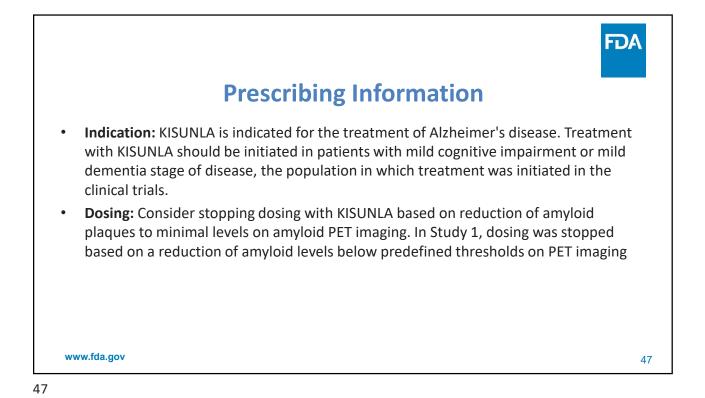


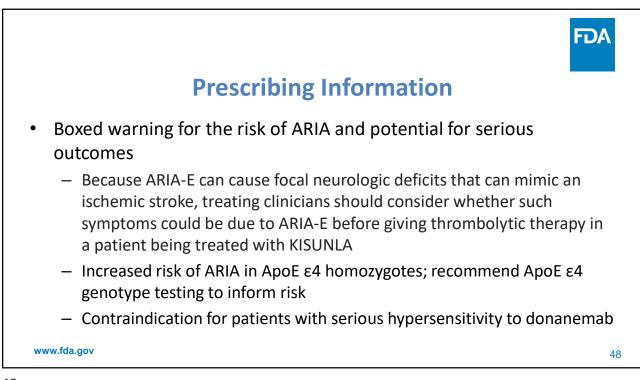




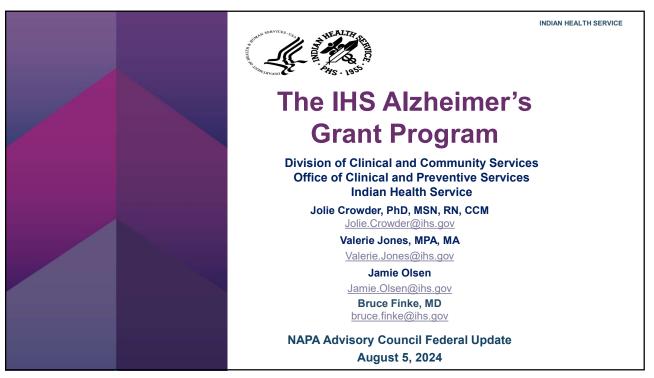


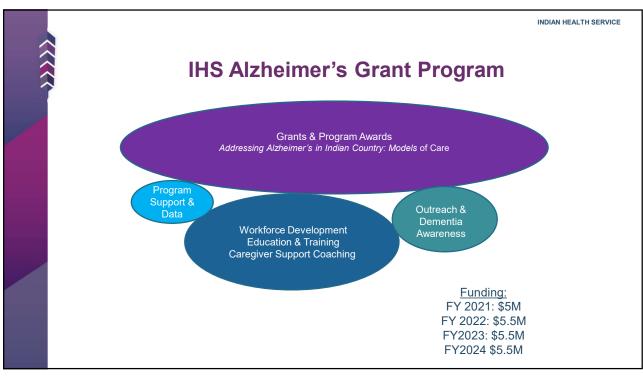


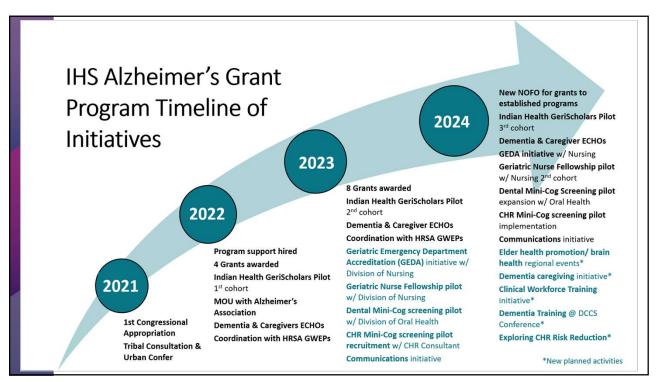


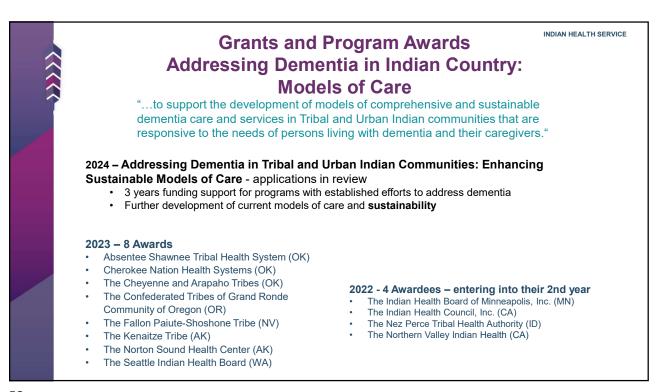


















Outreach and Awareness

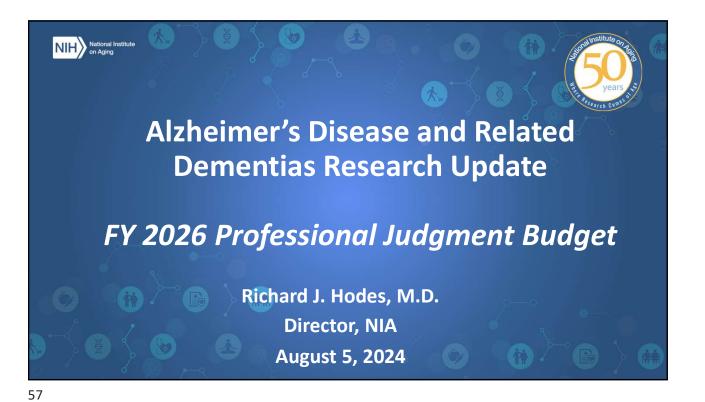
- Regional elder-focused health and wellness events in partnership with the Health Promotion and Disease Prevention program – Brain Health focus
- Communications support contract
- e-news, video and photo assets, website development
- National Caregiver Month blog and social media campaign
 Alzheimer's and older adult observances via social media
- Alzneimer's and older adult observances via social media
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- Tribal leader updates highlighting work across IHS, Tribal, and Urban Indian communities
- YouTube channel for training and webinars
- Online calendar of events
- Listserv and community continue to grow!

Program Support and Data

- · Enhanced Technical Assistance to IHS Grantees
- · Data Dashboard in development
- First Annual Report to Congress in review





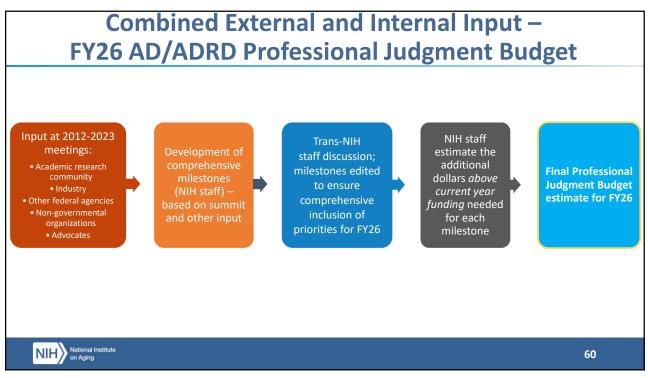


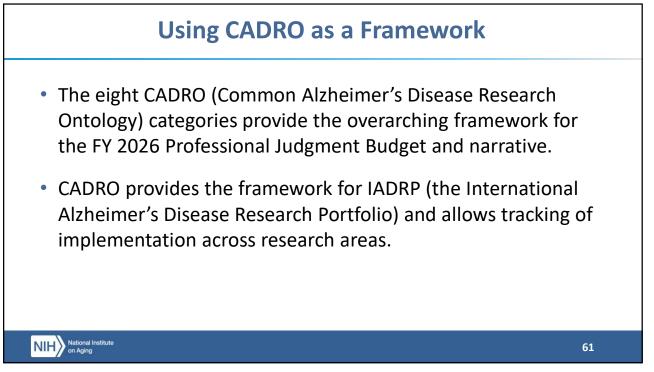


Professional Judgment Budget Language

SEC. 230. Hereafter, for each fiscal year through fiscal year 2025, the Director of the National Institutes of Health shall **prepare and submit directly to the President for review and transmittal to Congress, after reasonable opportunity for comment, but without change, by the Secretary of Health and Human Services and the Advisory Council on Alzheimer's Research, Care, and Services, an annual budget estimate** (including an estimate of the number and type of personnel needs for the **Institutes**) for the initiatives of the National Institutes of Health pursuant **to the National Alzheimer's Plan**, as required under section 2(d)(2) of Public Law 111–375.

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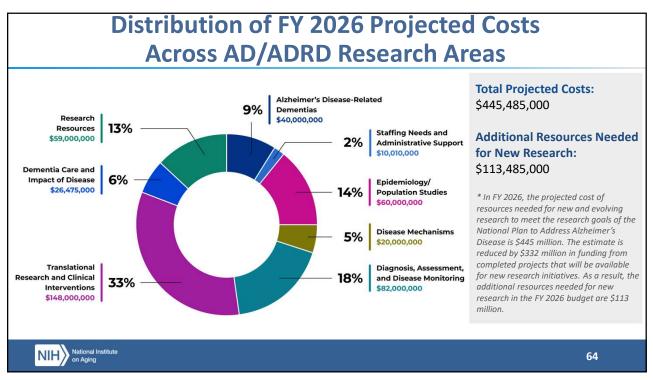


rojected Costs and Additional Resources Ne	
Professional Judgment Budget FY26 Additional Resources Needed	Amount
Epidemiology/Population Studies	\$60,000,000
Disease Mechanisms	\$20,000,000
Diagnosis, Assessment, and Disease Monitoring	\$82,000,000
Translational Research and Clinical Interventions	\$148,000,000
Dementia Care and Impact of Disease	\$26,475,000
Research Resources	\$59,000,000
Alzheimer's Disease-Related Dementias	\$40,000,000
Staffing Needs and Administrative Support	\$10,010,000
Total Costs for new AD/ADRD Research	\$445,485,000
Less: Funding from completed projects that is now available for new AD/ADRD research	(\$332,000,000)
Additional FY26 Resources Needed for New AD/ADRD Research	\$113,485,000

NIH National Institute

Professional Judgment Budget FY26 Total Resources Needed	Amount
FY24 NIH Estimate (based on FY24 enacted dollars) for AD/ADRD Research Spending (baseline estimate)	\$3,871,000,000
Additional FY26 Resources Needed for New AD/ADRD Research	\$113,485,000
Total FY26 Resources Needed for AD/ADRD Research	\$3,984,485,000





FY 2026 Professional Judgment Budget Narrative: Examples of Potential Future Research Opportunities



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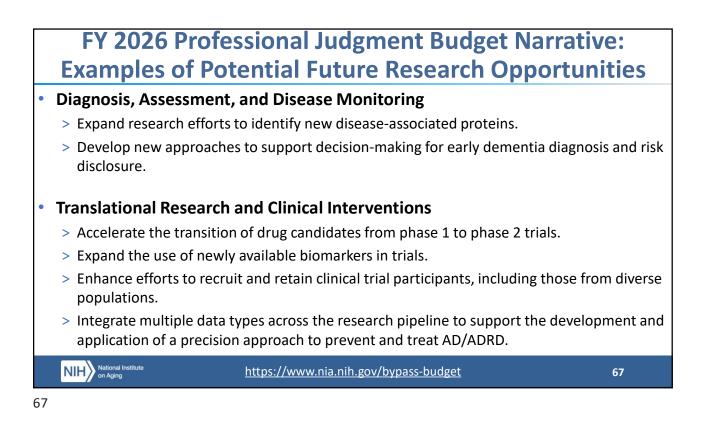
FY 2026 Professional Judgment Budget Narrative: Examples of Potential Future Research Opportunities

Epidemiology/Population Studies

> Expand research on genomic analyses of Alzheimer's and related dementias to better understand dementia risk and resilience.

Disease Mechanisms

- > Explore the role of the gut microbiome in dementia risk and resilience.
- > Expand research exploring the roles of brain immunity in dementia development.
- > Enhance understanding of the roles of abnormal proteins in dementia.
- > Examine the mechanisms underlying cognitive fluctuations associated with dementia.



FY 2026 Professional Judgment Budget Narrative: Examples of Potential Future Research Opportunities

Dementia Care and Impact of Disease

> Expand research on development and exploration of innovative care interventions and dementia care models.

Research Resources

> Expand efforts to enhance data in existing data resources to enable researchers to tackle new, more complex research questions.

Cross-cutting Area: International Studies

> Build capacity for community-engaged Alzheimer's and related dementias research, including research to understand and address the drivers of dementia health disparities in diagnosis, treatment, and outcomes.

https://www.nia.nih.gov/bypass-budget



Alzheimer's and Related Dementias Progress Report

 Summarizes significant NIH-funded dementia research advances from the last year.



https://www.nia.nih.gov/bypass-budget

