

Open Science, Big Data, and You

Working Together to Treat and Prevent
Alzheimer's Disease and Related Dementias

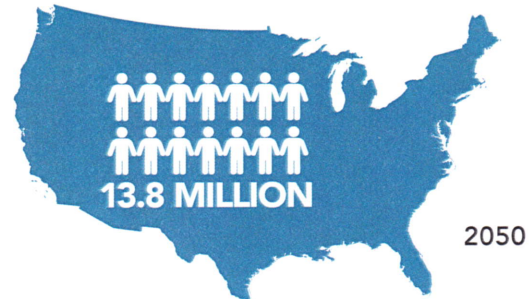
NIH BYPASS BUDGET PROPOSAL
FOR FISCAL YEAR 2020



The **National Institutes of Health (NIH)** presents an annual Professional Judgment Budget for the additional Federal funds needed to treat or prevent Alzheimer's disease and related dementias by 2025. This report outlines the toll Alzheimer's takes on our Nation and the scientific opportunities we could pursue with enhanced funding in Fiscal Year (FY) 2020. To view the entire NIH Professional Judgment Budget for FY 2020, visit www.nia.nih.gov/bypass-budget.

DEMENTIA AFFECTS MILLIONS OF AMERICANS

As many as **5.5 million** older Americans live with Alzheimer's disease. This number is expected to climb to nearly **14 million** by 2050, unless we find ways to stop the disease. Many thousands more live with related disorders—frontotemporal, vascular, Lewy body, and other types of dementia.



ALZHEIMER'S IS A LEADING CAUSE OF DEATH

Alzheimer's disease remains the **sixth leading cause of death** overall in the U.S., accounting for 4.1 percent of all deaths in 2015. It is the fifth leading cause of death among Americans age 65 and older.



DEMENTIA IS COSTLY

Alzheimer's is costly to families not only financially, but

in the sheer intensity of caregiving for a loved one with the disease. In 2011, nearly 6 million caregivers assisted older adults with dementia, devoting more than 6 billion hours per year in care. For the Nation, health and long-term care costs for dementia were estimated as high as **\$215 billion** in 2010; these annual costs may soar to **\$511 billion** by 2040.

BUDGETING NOW FOR A CURE IN 2025

NIH estimates we will need a **total of \$2.393 billion** in FY 2020 toward our goal of preventing and treating Alzheimer's disease and related dementias by 2025. In FY 2018, funding for this research was an estimated (enacted) \$1.9 billion. The Professional Judgment Budget presented here estimates \$876.7 million in additional funds needed relative to the FY 2019 President's budget proposal—comprising \$399 million to compensate for proposed reduced funding in FY 2019 and \$477.7 million in additional investment—to reach the 2025 goal.

Accelerating the Nation's Research in Alzheimer's & Related Dementias

The FY 2020 NIH Professional Judgment Budget for Alzheimer's Disease and Related Dementias highlights a transformative research agenda toward the national goal of treating or preventing Alzheimer's and related dementias by 2025. Read more about the research advances highlighted below at www.nia.nih.gov/bypass-budget.

Seeing the Complex Biology of Alzheimer's

Sophisticated new tools are allowing researchers to get a clearer picture of the complex underlying mechanisms of Alzheimer's disease and related dementias. NIH-supported scientists are advancing our understanding of beta-amyloid and tau protein structure and interplay, which could lead to the development of better imaging agents and therapies.

Building a Big Data, Open-Science Infrastructure

NIH is creating and strengthening an open-science infrastructure to enable rapid sharing of research methods, tools, and data that can address key challenges. Leveraging emerging digital technologies and big data approaches, researchers are able to speed target discovery and development, identify early markers of disease, and track responsiveness to treatment.

Laying the Foundation for Precision Medicine

Several efforts are underway to enable precision medicine—tailoring treatments to a person's unique disease-risk profile. The [Alzheimer's Disease Sequencing Project](#) is a big-data effort helping researchers to identify and share new genetic variants that influence risk and protective factors. The [Accelerating Medicines Partnership-Alzheimer's Disease](#) (AMP-AD) aims to discover novel therapeutic targets and develop biomarkers to validate existing targets.

Developing Therapies to Prevent or Delay Disease

To shorten the time between target discovery and drug development, the [AMP-AD Target Discovery and Preclinical Validation Project](#) is integrating the broad and rapid sharing of biological and analytic data. A growing number of preclinical projects are underway through the Alzheimer's Disease Drug Development Program. In 2017, NIH launched the [Alzheimer's Clinical Trials Consortium](#), the "next-generation" infrastructure designed for rapid start-up of clinical trials and support for imaging, biostatistics, data management, and recruitment.

Exploring Prevention and Risk Factors

Researchers are looking at the relationships between Alzheimer's or cognitive decline and many potential risk factors, including sleep, diet, education, and exposure to environmental toxins. A comprehensive report released in 2017, "[Preventing Cognitive Decline and Dementia: A Way Forward](#)," summarized the evidence so far, noting promising interventions and avenues for future research.

Engaging Scientific and Public Communities

Yearly research summits convene a diverse group of stakeholders to discuss research progress and priorities, including the [NIH Alzheimer's Disease Research Summit 2018: Path to Treatment and Prevention](#) and the 2017 [National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers](#). To engage and maintain public participation in research, a [National Strategy for Alzheimer's Disease Clinical Research Recruitment and Participation](#) is under development.

Improving Dementia Care and Assessment

NIH-funded investigators are gaining a better understanding of dementia care needs and interventions to support people with dementia and their caregivers through efforts such as the National Study of Caregiving, involving caregivers of people with and without Alzheimer's from the [National Health and Aging Trends Study](#). Through the Harmonized Cognitive Assessment Protocol (HCAP), national representative samples in the United States and in other countries, including Mexico, China, India, and England, are collecting data that will be comparable, enabling analyses of worldwide trends and differences in dementia epidemiology. NIA has funded several [small-business grants](#) for using technology to assist people with dementia and their caregivers.

Understanding Alzheimer's Disease-Related Dementias

Scientists are following many paths to better understand the complex biological and genetic risk factors and causes of Alzheimer's disease-related dementias. [MarkVCID](#) is a national consortium to accelerate the development and validation of biomarkers related to vascular contributions to cognitive impairment and dementia. Initiatives to develop biomarkers to help characterize and treat Lewy body dementia and frontotemporal dementia are also underway.

