Realizing the National Plan to Address Alzheimer’s Disease
Leadership Toward Treatment and Prevention
In 2011, the Alzheimer’s Association® worked with bipartisan champions in the House and Senate to pass the landmark National Alzheimer’s Project Act (NAPA), which mandated the creation of a national plan to fight Alzheimer’s. The first goal of the plan is to prevent and effectively treat Alzheimer’s by 2025.

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As a result, and because of the advocacy efforts of the Alzheimer’s Association and AIM, working alongside bipartisan policymakers, Congress has made Alzheimer’s research funding a priority, accelerating the accomplishments noted in this document.

But funding to fuel treatment and prevention has not come solely from the government. Generous philanthropists across the country have stepped up the pace, making contributions to the Association’s leading research efforts.

Together, we are achieving milestones for families and our country’s future.
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The Alzheimer’s Impact Movement (AIM) is a separately incorporated advocacy affiliate of the Alzheimer’s Association. AIM advances and develops policies to overcome Alzheimer’s disease through increased investment in research, enhanced care and improved support.

alzimpact.org
Molecular Pathogenesis and Physiology of Alzheimer’s Disease and Related Dementia

**NIH Leadership**

» Through the Molecular Mechanisms of the Vascular Etiology of Alzheimer’s Disease (M2OVE-AD) Consortium, researchers are seeking to better understand how heart and metabolic diseases and related factors (diabetes, cholesterol, blood pressure) may be involved in the onset and progression of dementia. **One of the key questions being addressed through the M2OVE-AD Consortium is the role of APOE and sex differences at the molecular level in the disease process.**

» With new high-resolution technology, researchers can see the shape and structure of tau at the molecular level for the first time. This NIH-funded work will enable researchers to further explore the role of tau in the progression of Alzheimer’s, frontotemporal (FTD) and other dementia.

» For the first time, NIH-funded researchers examined the genetic variants of people living with Dementia with Lewy bodies (DLB) in a large-scale study. The results suggest DLB shares certain biological pathways with Alzheimer’s and Parkinson’s, but also involves unique pathways, additional components of which are likely to be revealed by future genetic studies.

**Alzheimer’s Association Leadership**

» To advance knowledge around sex- and gender-based differences, the Association convened a think tank to further research in this area, leading to an ongoing grant program. The Association has awarded more than $3.2 million to 16 research grants that aim to understand why more women than men develop the disease — and how we can treat it in both genders. The Alzheimer’s Association International Conference® (AAIC®) continues to highlight this critical research in its annual program.

» A team supported by the NIH and the Alzheimer’s Association discovered an individual who, despite having the dominantly inherited Alzheimer’s gene, remained cognitively intact until her 70s. The individual has two copies of another rare gene mutation known as the Christchurch variant which the researchers believe is the source of this individual’s dementia resistance. If confirmed, this discovery could lead to new possibilities for dementia treatment.

» Since the passage of NAPA, the Alzheimer’s Association has continued its leadership commitment to Alzheimer’s research, awarding 392 grants through its International Research Grants Program to projects investigating the basic biological underpinnings of the disease in order to accelerate pathways to treatments.
The Accelerating Medicines Partnership-Alzheimer’s Disease (AMP-AD) Biomarkers Project is supporting the addition of tau imaging to NIH-funded Phase II/III secondary prevention. The Alzheimer’s Association is the only nonprofit member on the AMP-AD steering committee. Data from the trials will be made broadly available via the Global Alzheimer’s Association Interactive Network (GAAIN), a global data-sharing platform.

Through the Longitudinal Early-Onset Alzheimer’s Disease Study (LEADS), researchers are working to understand early-onset Alzheimer’s. LEADS is a 15-site NIH-funded study, bringing together academic teams, the Alzheimer’s Association and other industry and advocacy groups to collect detailed cognitive, clinical and biomarker data. The Association is funding a $1 million add-on study to allow researchers to investigate the entire genome of all 600 participants to better understand the role of genes in the development of the disease. The data will be made available to the scientific community through GAAIN.

Scientists are further exploring the impact race may have on dementia risk, which could lead to refined diagnosis and treatment options. One team found mixed diagnoses and cerebrovascular disease are more common in Hispanics and blacks than non-Hispanic whites.

Following the NIH’s $8 million investment to investigate vascular-related imaging biomarkers at the University of Southern California, the Association contributed an additional $3 million to add PET amyloid and tau imaging to the study — providing an unparalleled picture of how the neurovascular system plays a role in Alzheimer’s disease initiation and progression. The study found that individuals with early cognitive dysfunction develop brain capillary damage and blood-brain barrier breakdown even without tau and amyloid biomarker changes.

The Alzheimer’s Association made a research grant of $8 million to support the Longitudinal Evaluation of Amyloid Risk and Neurodegeneration (LEARN) Study as a companion study to the Anti-Amyloid Treatment in Asymptomatic Alzheimer’s Disease (A4) Study. This marked the first time researchers have collected images of both tau and amyloid simultaneously in an Alzheimer’s prevention trial, this baseline data is available to the scientific community through GAAIN.

In September 2018, the Alzheimer’s Association launched Project ECHO for Person-Centered Dementia Care in Assisted Living Communities and Project ECHO for Dementia Diagnosis and Care focused on primary care. The programs include a team of experts conducting biweekly virtual “clinics” through video conferencing with community care teams. Project ECHO provides a forum to explore real case studies from the field in order to better address the common challenges facing communities that provide dementia care.

Scientists are exploring how imaging technology in ophthalmology could be used to measure levels of amyloid in eyes. In May 2019, the Alzheimer’s Association convened a retinal imaging workshop for the scientific community to further discuss how this approach may provide the ability to detect Alzheimer’s in earlier stages before symptoms appear.

The Imaging Dementia — Evidence for Amyloid Scanning (IDEAS) Study, led by the Alzheimer’s Association and managed by the American College of Radiology, is assessing the impact brain amyloid PET imaging has on outcomes for people with cognitive impairment, such as earlier counseling and access to more appropriate drugs. In addition, the National Institute on Aging (NIA) and the Association are funding ancillary studies on care, blood biomarkers and genetics.
NIH Leadership

» The NIA is funding two ancillary studies to the Alzheimer’s Association’s U.S. POINTER clinical trial. The Neuroimaging Ancillary Study, expected to total $47 million over five years, will allow for PET imaging to measure amyloid and tau proteins, and MRIs to measure details in the brain including volume, white matter integrity and blood flow. These measurements will tell how effective the interventions are and provide important information about the underlying biology of brain health. The POINTER-zzz (sleep) ancillary study, expected to total $5.5 million over five years, will examine whether lifestyle changes might improve sleep quality in a subset of 700 participants in U.S. POINTER. Chronic sleep disturbances have been linked to an increased risk of cognitive decline and Alzheimer’s.

» To diversify and reinvigorate the Alzheimer’s drug development pipeline, the NIH launched the TREAT-AD Consortium, comprised of two cross-disciplinary and multi-institutional research centers. The NIH funding is expected to total more than $73 million over the next five years, and data and research tools generated by the Consortium will be made available to researchers from academic and industry settings.

» Through the SPRINT MIND Study, NIH-supported researchers discovered that aggressive lowering of systolic blood pressure significantly reduces the risk of mild cognitive impairment (MCI) and the combination of MCI and dementia.

» The NIH-funded Alzheimer’s Clinical Trials Consortium (ACTC) seeks to accelerate and expand testing of therapies of all stages Alzheimer’s and other dementias. ACTC — comprised of 35 sites across the U.S. — is developing strategies for inclusion of diverse populations in clinical trials.

» The PEACE-AD trial run through the Alzheimer’s Disease Cooperative Study (ADCS) is testing whether prazosin, an FDA-approved drug developed decades ago to treat high blood pressure, can reduce disruptive behavior in people with moderate to severe Alzheimer’s disease. This study was funded by the NIA with additional funding provided by the Alzheimer’s Association.

Alzheimer’s Association Leadership

» The Association is funding and implementing U.S. POINTER, a two-year clinical trial to evaluate whether lifestyle inventions that simultaneously target many risk factors protect cognitive function in older adults who are at increased risk for cognitive decline. Five sites across the U.S. have been selected and recruitment for the trial began in 2019.

» Part the Cloud, a movement founded by philanthropist Michaela Hoag, works in partnership with the Alzheimer’s Association to fund research awards that accelerate findings from the laboratory, through trials and into possible therapies — filling the gap in Alzheimer’s drug development by supporting early phase clinical studies. In November 2019, Bill Gates joined the effort, funding a $10 million award. The Alzheimer’s Association, working through Part the Cloud, will raise $20 million, doubling the total research investment to $60 million.

» Preliminary results of the NIH-support SPRINT MIND Study were presented at AAIC 2018 and published in the January 2019 issue of the Journal of the American Medical Association, providing the strongest evidence to date that there are actions individuals can take to reduce their combined risk of developing MCI and dementia. The Alzheimer’s Association is funding a two-year add-on study — SPRINT MIND 2.0 — to further examine the impact of blood pressure on dementia risk.

» The NIA-AA Research Framework: Towards a Biological Definition of Alzheimer’s Disease revised guidelines was developed, following the Alzheimer’s Association and the NIA hosted workgroup to develop a strategy and framework to advance research on our understanding of the pathophysiology of Alzheimer’s and the development and progression of the disease.
Epidemiology

**NIH Leadership**

» The Atherosclerosis Risk in Communities (ARIC) Study, one of the largest and longest studies of black and white Americans, is designed to evaluate vascular risk factors. The NIH is funding an ancillary study, ARIC-PET, designed to evaluate the contribution of these vascular risk factors specifically to the deposition of amyloid in the brain as measured through PET scans.

» The Study of Latinos—Investigation of Neurocognitive Aging (SOL-INCA) is seeking to fill major gaps in the understanding of why these disorders may disproportionately affect Latinos compared to other Americans. One group of researchers estimates that 9.8% of middle-age and older Latinos met the criteria for MCI. They also found older age, high cardiovascular disease risk and symptoms of depression increased with MCI prevalence, but that ApoE4 was not associated with increased MCI risk in the Latino groups studied.

**Alzheimer’s Association Leadership**

» The Alzheimer’s Association is funding an effort by the NIH-supported Health and Retirement Study (HRS) to pilot the feasibility of giving participants a PET scan to determine amyloid deposition in the brain.

» The Alzheimer’s Association, through a cooperative agreement with the CDC, secured the first-ever national data set on subjective cognitive decline. Through the Behavioral Risk Factor Surveillance System (BRFSS) survey, the Alzheimer’s Association worked with public health agencies to obtain this data.

» The Alzheimer’s Association Alzheimer’s Disease Facts and Figures report is the definitive annual compilation of national statistics and information examining incidence and risk factors and conveying the impact of dementia on individuals, families, government and the nation’s health care system.

Care, Support and Health Economics of Alzheimer’s Disease

**NIH Leadership**

» The NIH is funding dementia care research across care settings to improve quality of life for people living with Alzheimer’s and other dementias. Researchers are examining how the availability of specialized care, long-term services and supports, and clinical consulting can contribute to better outcomes.

» In November 2019, the NIH awarded a grant to the Alzheimer’s Association to fund Leveraging an Interdisciplinary Consortium to Improve Care and Outcomes for Persons Living with Alzheimer’s and Dementia (LINC-AD). The goal of LINC-AD is to strengthen the current framework for psychosocial research examining care for people living with dementia and their care partners. The program will create an international consortium of researchers and stakeholders (persons living with dementia, care partners and care providers) that will review existing measures, identify and address gaps, and disseminate these results via permanent online repositories of recommended measures and shareable data.

**Alzheimer’s Association Leadership**

» The Alzheimer’s Association launched the Consultant Impact Study, a pilot research program reviewing a sample of care consultation calls completed through the Association’s 24/7 Helpline. The study found the Helpline is effective at reducing caregiver emotional distress and improving the ability of callers to “take action.” As a result of the success of the pilot, the Association launched the Care Consultation Intervention Study to further assess the impact of telephone-based care consultation on caregivers.

» The Alzheimer’s Association released the 2018 Dementia Care Practice Recommendations (DCPR), quality care practices based on a comprehensive review of current evidence, best practices and expert opinion. These person-centered recommendations better define quality care across all care settings and throughout the disease course. In July 2019, the Association launched the DCPR Pilot Program, which seeks to implement and evaluate a consultative coaching model focused on the adoption of the practices. This implementation project is focused on six assisted living facilities in Dayton, Ohio.

» Through an Administration for Community Living grant, the Association is conducting a study on how to improve financial well-being of seniors and caregivers and better equip them for financial caregiving tasks.
With the goal to shorten the time to develop effective therapies for Alzheimer’s treatment and prevention, the NIH launched the public-private partnership AMP-AD. The program developed cloud-based infrastructure to more easily and quickly share data and methods. The infrastructure is comprised of the NIH-funded AD Knowledge Portal and Agora platform, as well as the Alzheimer’s Association data hub GAAIN.

The NIA is modernizing and transforming the Alzheimer’s Disease Research Centers (ADRC) program. By integrating transformative recommendations from an expert panel, the ADRCs will be better able to achieve the objectives of the national plan. The next generation of ADRCs will increase flexibility and collaboration by leveraging expanded resources, capabilities and research participants across the network.

Through the Model Organism Development and Evaluation for Late-Onset Alzheimer’s Disease (MODEL-AD) supported by the NIH, scientists are developing and characterizing 50 new mouse models that better reflect late-onset Alzheimer’s disease. The mouse models are made widely available to academic and other researchers.

Consistent with the national plan, the National Institute of Neurological Disorders and Stroke hosted the Alzheimer’s Disease–Related Dementias Summit 2019, bringing together Alzheimer’s and dementia experts to address special research priorities for Alzheimer’s–related dementias, including FTD, Lewy body, mixed and vascular dementias. During the meeting, participants reviewed and assessed the progress on the research recommendations developed by past ADRD summits, and developed new recommendations based on the current status of science.

The NIA, in partnership with the Alzheimer’s Association, provided an update on the National Strategy for Recruitment and Participation in Alzheimer’s Disease Clinical Research in July 2018. The new national strategy identifies actions to increase recruitment and participation among diverse audiences.

The NIH launched the All of Us research program, a historic effort to gather data from at least 1 million Americans to accelerate research, improve health and enable precision medicine for diseases including Alzheimer’s. The Alzheimer’s Association is a champion partner helping to raise awareness of the program.

The Alzheimer’s Association, working with the NIH, convened a meeting of the AMP-AD Target Discovery and Preclinical Validation Project. The workshop of leading dementia experts focused on discovering novel, clinically relevant therapeutic targets and on developing biomarkers to help validate existing therapeutic targets.

GAAIN is an online gateway to a vast collection of Alzheimer’s disease research data and sophisticated analytical tools. It is the only live platform in Alzheimer’s research today that allows users to log on from a web browser and dynamically interact with imaging, genetic, behavioral and other data. GAAIN includes 30,000 unique data attributes linking together over 500,000 research participants’ data. In 2019, over 3,000 investigators from 80 countries and nearly every continent utilized the GAAIN interface for their research needs.

To increase clinical trial participation, the Alzheimer’s Association provides TrialMatch®, a free, easy-to-use clinical studies matching service that generates customized lists of studies based on user-provided information. Designed for individuals living with Alzheimer’s, caregivers and healthy volunteers, the continually updated TrialMatch database contains more than 400 studies at sites across the country and online. There are over 350,000 users in TrialMatch.

The Alzheimer’s Association International Conference® (AAIC®) is the world’s largest and most influential international meeting dedicated to advancing dementia science. In 2019, nearly 6,000 leading researchers, clinicians, investigators and care providers from 60 countries gathered in Los Angeles. AAIC is dedicated to advancing discussions on new areas of Alzheimer’s and dementia exploration by hosting experts with differing views on emerging, provocative topics such as viruses and bacteria.

The Alzheimer’s Association has convened multiple meetings bringing together key scientists from the research fields of Down syndrome and Alzheimer’s. A 2015 meeting articulated a set of research priorities to move the field forward that includes investigating shared pathological mechanisms, identifying unique biomarkers that might differentiate DS/AD from other types of early or late-onset Alzheimer’s, and the discovery and validation of novel therapeutic targets.
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The Alzheimer’s Association leads the way to end Alzheimer’s and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

Our vision is a world without Alzheimer’s and all other dementia™.

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