



Heartbreak and Hope:

Meeting the Needs of Older Americans

2021 Impact Report

Over the past year, the Alliance for Aging Research staff persisted in stepping forward to advocate for access to research, innovation, and quality care for everyone as they age. To say the year 2021 was challenging is truly an understatement. COVID-19 has profoundly affected everyone's wellbeing. Older adults continue to experience barriers as they navigate their way through the pandemic, as well as the rampant intolerance that came to a tipping point over the last year. This report not only summarizes the Alliance's programmatic and fiscal achievements for 2021, it demonstrates our resolve to help fix negative social determinants that undermine healthy aging equity for any group.

Our aim is to inspire people of all ages to collectively support innovation and social structures that enhance independence and dignity, and promote health. In 2021, the Alliance launched materials that shared the truth about vaccines and combatted common misinformation and disinformation leading to vaccine hesitancy; celebrated the 5th anniversary of Heart Valve Disease Awareness Day; and dispensed "Wellness Wisdom" to increase awareness of Medicare preventive services. With our partners, we served as a trusted resource on the COVID-19 vaccine science, regulatory, and distribution process; worked to improve clinical care for nursing home residents living with neuropsychiatric symptoms of dementia; led the way to improve affordability for patients by advocating for Congress to cap and smooth out-of-pocket costs in Medicare Part D; and led the charge against discriminatory prescription drug price setting proposals. Through it all, we continued to Talk NERDY, educate, and advocate on the research and health issues that matter for older adults.

We are pleased to share with you our 2021 impact report. We are thankful for our **Board of Directors** for their ongoing leadership and **our supporters** who champion our mission in countless ways. We truly appreciate your extra encouragement and our shared commitment to healthy aging for all.



Sue Peschin, MHS
President and CEO



The Alliance for Aging Research is the leading nonprofit organization dedicated to accelerating the pace of scientific discoveries and their application to vastly improve the universal human experience of aging and health. The Alliance believes advances in research help people live longer, happier, more productive lives and reduce healthcare costs over the long term.

For more than 35 years, the Alliance has guided efforts to substantially increase funding and focus for aging at the National Institutes of Health (NIH) and the Food and Drug Administration (FDA); built influential coalitions to guide groundbreaking regulatory improvements for age-related diseases; and created award-winning, high-impact educational materials to improve the health and well-being of older adults and their family caregivers.

Financials

\$4,325,291

FY21 Total Revenue



CHARITY NAVIGATOR
★★★★★ Four Star Charity

For more information about the Alliance's financials, visit AgingResearch.org/Financials.

Heroes in Health Annual Celebration

This important event virtually brought together 300 guests at the 2021 Roundtable Discussion and the 28th Bipartisan Congressional Awards. [Watch the Awards celebration online.](#)



CLAUDE PEPPER AWARD FOR
ADVANCING HEALTHY AGING
Senator Chris Van Hollen (D-MD)
United States Senate



SILVER INNOVATOR AWARD
Dr. Kizzmekia S. Corbett
Harvard T.H. Chan School of Public Health



DISTINGUISHED PUBLIC SERVICE AWARD
Congressman Brett Guthrie (R-KY)
U.S. House of Representatives



PERENNIAL HERO AWARD
Phyllis Greenberger, MSW
HealthyWomen



DANIEL PERRY FOUNDER'S AWARD
President Jonathan Nez and Dr. Jill Jim
on behalf of the **Navajo Nation**



2021 Board of Directors

CHAIR

James G. Scott

President and CEO,
Applied Policy, LLC

CHAIR EMERITUS

John L. Steffens

Founder and Senior
Managing Partner,
Spring Mountain Capital, LP

VICE CHAIR

Michele Markus

Head of Global Health
Accounts; Worldwide
Enterprise Lead,
Omnicom Health Group

TREASURER

William Schuyler

Vice President of
Government Relations,
GlaxoSmithKline

SECRETARY

Mark Simon

Partner and Co-Founder,
Torreya Partners, LLC

MEMBERS

John Alam, M.D.

Founder and CEO,
EIP Pharma, LLC

George Beach

Founder and Chairman,
Beach Creative
Communications

Mary Bordoni

Director of Strategic
Alliance Development,
Bristol-Myers Squibb
Company

Margaret H. Davis-Cerone

Senior Director of Corporate
Affairs - U.S. Policy,
Pfizer, Inc.

James E. Eden, Ed.D.

President,
The Eden Group, LLC

Karen Gally

Associate General Counsel,
Otsuka America
Pharmaceutical, Inc.

Kelsey Lang

Senior Director,
Public Affairs - Policy,
Novo Nordisk

Dan Perry

Founder,
Alliance for Aging Research

Calvin W. Schmidt

Sr. Vice President and
World Wide Leader,
Government Affairs & Policy,
Johnson & Johnson

John Whyte, M.D., M.P.H.

Chief Medical Officer,
WebMD

Staff

For a full staff list, visit AgingResearch.org/Staff.

Action to Advance Aging



Aging In Motion

In 2021, Aging in Motion (AIM) continued its national consumer campaign to educate older adults and healthcare providers about sarcopenia. AIM's educational videos had over 53,000 views on YouTube and 550,000 views on Facebook. The campaign also conducted a national survey with medical providers to identify gaps for the screening, diagnosis, and treatment of sarcopenia. AIM also partnered with the Office of Women's Health within the Department of Health and Human Services on an educational campaign to address behavioral changes that decrease the risk of sarcopenia.

[Visit AgingInMotion.org](https://AgingInMotion.org).

COVID-19 VACCINE EDUCATION *and* EQUITY PROJECT

CVEEP

The COVID-19 Vaccine Education and Equity Project is a national coalition that serves as a trusted resource on the COVID-19 vaccine science, regulatory, and distribution process; and to promote dialogue and action to ensure equitable access. Led by the Alliance, HealthyWomen, and the National Caucus and Center on Black Aging, Inc., the project involves more than 200 partner organizations representing patients, caregivers and families, diverse communities, healthcare workers, older Americans, veterans, frontline workers, scientists, and more. **[Visit COVIDVaccineProject.org](https://COVIDVaccineProject.org).**

Pancakes for Prevention

A major project of the CVEEP, the Pancakes for Prevention program was a collaboration with national organizations like The Grange and USA Boxing, aimed at combatting vaccine hesitancy at the community level. Dozens of events across the country integrated vaccine messaging with community events to reach people where they work and play.

Alzheimer's and Dementia



ACT-AD

The coalition held its 13th Annual FDA/ACT-AD Allies Meeting in February, focusing on clinical links between different forms of dementia. ACT-AD also held educational webinars, including one exploring the public and private research funding ecosystem for Alzheimer's disease. The coalition also contributed to patient advocacy efforts for continued investment into foundational research at the NIH. [Visit ACT-AD.org](https://act-ad.org).

Emerging Therapies for Alzheimer's Disease

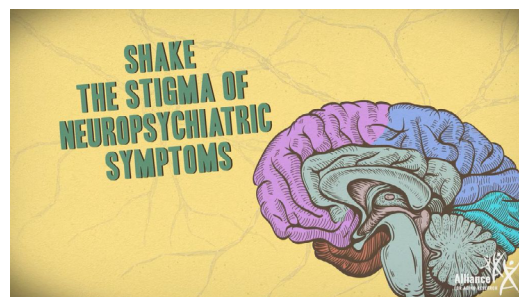
In 2021, the FDA approved the first drug, a monoclonal antibody, with the potential to modify or delay the progression of Alzheimer's disease. Soon after, the Centers for Medicare and Medicaid Services (CMS) initiated a review process to determine if Medicare patients will have access to FDA-approved monoclonal antibody treatments for Alzheimer's disease. The Alliance submitted comments to CMS encouraging coverage for current and future therapeutics impacted by the agency's decision. A final coverage determination will occur in 2022.

Project PAUSE



Project PAUSE (Psychoactive Appropriate Use for Safety and Effectiveness) submitted public comments to the U.S. Senate Finance Committee's request on unmet mental health needs, including protecting access to critical medicines, access to long-term care for individuals with mental health challenges, determining appropriate use of antipsychotics, and long-term care workforce mental health. [Visit AgingResearch.org/ProjectPAUSE](https://agingresearch.org/projectpause).

Neuropsychiatric Symptoms



The Alliance created new educational films on how diseases and injuries to the brain can impact how we interact with the world and lead to significant and disabling behavioral and psychological symptoms—known as neuropsychiatric symptoms—that can be treated but are too often stigmatized. [Visit AgingResearch.org/Neuropsychiatric-Symptoms](https://agingresearch.org/neuropsychiatric-symptoms).



Drug Pricing

Institute for Clinical and Economic Review

On May 12, the Alliance released a report, “Assessing the Value of Therapies in Alzheimer’s Disease: Considerations to Create a Practical Approach to Value,” which the Alliance commissioned from Milliman. This report outlines a new framework for assessing the value of Alzheimer’s treatments, and describes how the traditional economic approach advanced by ICER to measure the value of therapeutics fails to address the challenges posed by Alzheimer’s disease. The report findings and implications were discussed during a webinar on May 18. [Visit ICERFacts.org](https://www.icerfacts.org).

Vital Transformation White Paper

In April, the Alliance, in collaboration with Vital Transformation, released the results of a new analysis, which found that implementing international reference pricing in the U.S. would sharply reduce the ability to fund Alzheimer’s disease research, further diminishing investments and progress in this disease area. The analysis was released in conjunction with a letter to Congressional leadership that was signed by over 30 patient advocacy groups and urged Congress to keep any international reference pricing proposals out of drug pricing reform legislation. [Visit AgingResearch.org/VitalTransformation](https://www.agingresearch.org/vitaltransformation).

Project LOOP

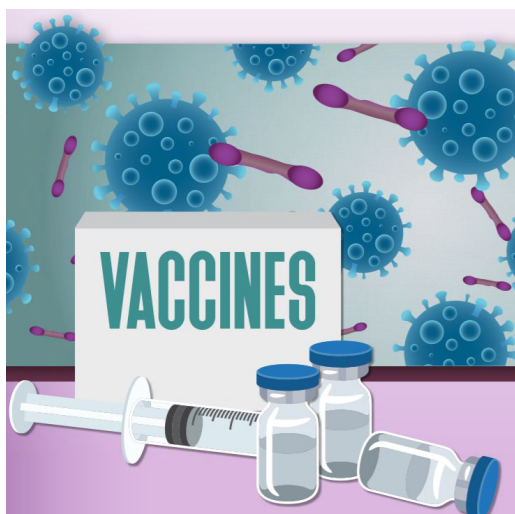
Project LOOP (Lower Out-of-Pocket Costs in Medicare Part D Now), an ad hoc coalition effort, led discussions on affordability including 70+ meetings with Capitol Hill staff in 2021. Achievements included the development of patient-centered principles for cost smoothing, direct language contributions to two Medicare Part D reform bills, a letter to key House and Senate committee leaders calling for meaningful reforms to improve affordability signed by more than 130 advocacy organizations, and multiple thought leadership pieces in *The Hill* and *Morning Consult*. Project LOOP also hosted webinars featuring Rep. Scott Peters (D-CA) and Douglas Holtz-Eakin, former director of the Congressional Budget Office. [Visit LowerOutOfPocketCosts.org](https://www.loweroutofpocketcosts.org).

International Reference Pricing

The Alliance submitted comments to CMS on the Most Favored Nation (MFN) model, an analogue of international reference pricing, followed by the agency retracting the model. International reference pricing would restrict coverage for many therapies and rely on methodologies that discriminate against people with disabilities, older adults, and communities of color. The Alliance previously filed an amicus brief in support of a federal injunction to prevent the implementation of the MFN, which was successful. Additionally, the Alliance worked with offices on Capitol Hill to remove international reference pricing proposals from Medicare Part D reform legislation. Related opinion pieces were featured in *STAT*, *Morning Consult*, and the journal *Health Affairs*.

QALY Impact on Racial and Ethnic Groups

The Alliance worked with Charles River Associates on a white paper that examined the impact of Quality-Adjusted Life Years (QALYs) on Black and Latinx persons with Alzheimer’s disease in Australia, Canada, and the United Kingdom. The report found that “the true value of new medicine to specific groups in society is not captured through QALY-based value assessment, which reinforces health inequities in coverage and access decisions.” [Visit AgingResearch.org/QALY](https://www.agingresearch.org/qaly).



Our Best Shot

New resources in the Our Best Shot campaign include a film on the importance of the influenza vaccine in keeping older adults and their families healthy, and a fact sheet that shares the truth about vaccines and combats common misinformation and disinformation that is leading to vaccine hesitancy. These resources produced more than two million impressions in three months.

Visit AgingResearch.org/OurBestShot.



Nutrition and Aging

The Alliance created a new educational film and Spanish translation on how the way we eat throughout our lives impacts the way we age. It shares important information on changing nutritional needs with age, nutrition-related diseases, dietary guidelines from the U.S. Department of Agriculture, and the impact of food insecurity on healthy nutrition. The films reached more than 800,000 people.

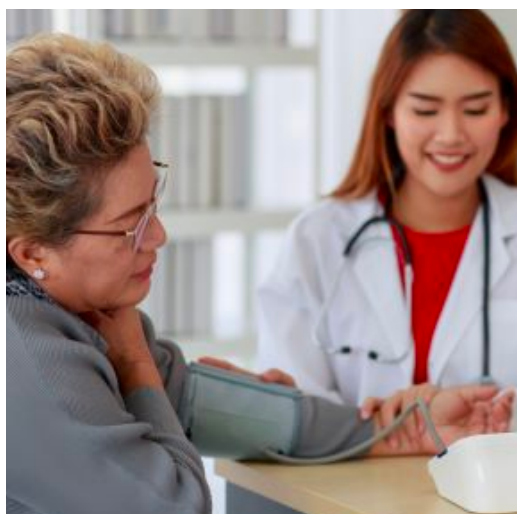
Visit AgingResearch.org/Health-Topic/Nutrition.



Talk NERDY to Me

The Alliance virtually educated 36 older adult patients, family caregivers, and researchers on patient-centered outcomes research at the 2021 Talk NERDY to Me training. The Alliance helped them get involved in advisory roles on clinical trial committees, comparative clinical effectiveness studies, and other research, policy, and health education-focused opportunities.

Visit AgingResearch.org/NERDY.



Wellness Wisdom

The Alliance released a new fact sheet with important details on preventive services through Medicare—including what to expect at yearly medical visits, how to prepare for visits, how much preventive services cost, and a closer look at vision and cognitive screening services. Outreach for this resource reached more than 300,000 people.

[Visit AgingResearch.org/WellnessWisdom](https://AgingResearch.org/WellnessWisdom).



CELEBRATING FIVE YEARS

Valve Disease Awareness Day

The Alliance celebrated five years of raising awareness about valve disease and the importance of listening to your heart with more than 100 partners and thousands of advocates. Over five years the campaign has produced more than one billion impressions.

[Visit ValveDiseaseDay.org](https://ValveDiseaseDay.org).



Year Without a Stroke

The Alliance expanded the Celebrating a Year Without a Stroke Campaign to include resources on venous thromboembolism and coronary artery disease/peripheral artery disease, in addition to atrial fibrillation. New patient videos provide a personal look at the devastating impact of these diseases and reached more than 1.3 million people.

[Visit YearWithoutAStroke.org](https://YearWithoutAStroke.org).



We at the Alliance for Aging Research thank you for taking the time to explore the impact we had in 2021. We are grateful for the Alliance's community of support and partnership, which allows us to do meaningful work.

Though new challenges appear before us in the new year, we remain hopeful that a healthier tomorrow rests ahead. We look forward to another year of improving the lives of aging Americans. Stay connected with us and our work at www.AgingResearch.org.