



# Changing the Narrative to Achieve Healthy Aging and Equitable Access

## 2023 Impact Report

In 2023, we faced mounting cognitive dissonance about aging. The social narrative was often a contradiction between “80 is the new 60” and ageist protests to end the so-called “gerontocracy” running the country. At the same time, our society struggled to address how structural racism and other negative social determinants accelerate aging and the onset of the chronic diseases that accompany it. Clinical care was more rushed than ever for both clinicians and their patients. And cost control ruled above all, as healthcare systems shut their eyes and held their ears in refusal to reconcile increased resource needs for the health and well-being of our rapidly aging society.

At the Alliance, we thought the COVID-19 pandemic would be a wake-up call for America about how we care for older adults. Instead, we found that—while many of us may love our own parents or grandparents—our cultural fears of aging disconnected us from solution-based dialogue.

We needed to address this cognitive dissonance head on. As the Alliance forged ahead in our 2023 health education and public policy efforts, we updated our organization’s **mission and vision** to be more explicit:

**Mission: The Alliance for Aging Research is dedicated to changing the narrative to achieve healthy aging and equitable access to care.**

**Vision: The Alliance strives for a culture that embraces healthy aging as a greater good and values science and investments to advance dignity, independence, and equity.**

Nothing we do at the Alliance is done by just one person alone, and in fact, our strength comes from being dependent on each other in pursuit of our common goals—these include our Alliance **board members**, our supporters, and our many advocacy partners. We are so proud of the **individuals** who work at the Alliance every day. They are super smart, motivated, and kind—a true team of people who are essential to each other’s success and to ours. Everything in this report is from them and due to them.

We have to do more together if we truly want to achieve healthy aging and equitable access for everyone. As the African proverb says, “If you want to go fast, go alone. If you want to go far, go with others.” We thank you for traveling with us in 2023 and we look forward to charting a path of hope and resilience in the year ahead.

Warmly,



*Michele Markus*

**Michele Markus**

Chair, Board of Directors



*Sue Peschin*

**Sue Peschin, MHS**

President and CEO



## Mission

The Alliance for Aging Research is dedicated to changing the narrative to achieve healthy aging and equitable access to care.

## Vision

The Alliance strives for a culture that embraces healthy aging as a greater good and values science and investments to advance dignity, independence, and equity.

## Financials

# \$3,921,232\*

FY23 Total Revenue

\* This figure represents an unaudited amount. The total revenue will be updated upon completion of the audit in the first quarter of 2024.

For more information about the Alliance’s financials, visit the [Financial Reports & Funding](#) section of our website.

For over 35 years, the Alliance for Aging Research has maintained its reputation as a trusted source. We are transparent about our partnerships and activities, including how our programs are funded and by providing access to our financial reports.



The Alliance for Aging Research is a recipient of Candid’s Platinum Seal of Transparency.



The Alliance for Aging Research is rated a 4-star charity by Charity Navigator.

# 2023 Board of Directors

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## Alliance Staff



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**Katrin Werner-Perez**  
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**Willard Ramsey**  
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**Chris Yun, MS**  
Development Coordinator



**Katie Riley**  
Vice President of Communications

## Award-Winning Work



The Alliance for Aging Research is a recipient of The Telly Awards 44th Annual Gold Medal. In June, the Alliance was awarded **two Gold Telly Awards** in recognition of exemplary educational videos.

# Heroes in Health 30<sup>th</sup> Anniversary Celebration



The Alliance celebrated our 30<sup>th</sup> anniversary *Heroes in Health* event on September 26 at the iconic Waldorf Astoria in Washington, DC with more than 320 guests who gathered with us to celebrate “Integrity, Collaboration, and Healthy Aging.”

The festivities kicked off with the 2023 Conversation with CMS: “Coverage, Affordability, Access, and Quality for the Medicare Population” moderated by Alliance Board Chair James “Jim” Scott and featured panelists:

- Doug Jacobs, MD, Chief Transformation Officer, Centers for Medicare & Medicaid Services (CMS)
- Amanda Bartelme, Executive Director of Policy, Eisai Inc.
- Molly Burich, MS, Senior Director of Public Policy and Government Affairs, Otsuka America Pharmaceutical, Inc.
- Michael Ward, MS, Vice President of Public Policy and Government Relations, Alliance for Aging Research

Our Conversation with the FDA: “Future of Breakthrough Therapy Designation and Clinical Trial Design in Age-Related Diseases” was moderated by Alliance President and CEO Sue Peschin, MHS, and featured panelists:

- Hilary Marston, MD, MPH, Chief Medical Officer, U.S. Food and Drug Administration (FDA)
- Sean Curtis, MD, MPH, Senior Vice President of Regulatory Affairs, Merck Research Labs
- Nadim Geloo, MD, Senior Medical Director, Abbott Structural Heart at Abbott Laboratories
- Candace DeMatteis, JD, MPH, Policy Director, Partnership to Fight Chronic Disease (PFCD)

# Heroes in Health 30<sup>th</sup> Anniversary Celebration



**Congresswoman Anna G. Eshoo (D-CA)** accepts the Claude Petter Award for Advancing Healthy Aging from Tom Spulak, Chairman and President of the Claude Pepper Foundation. This award is presented each year to a Democratic member of Congress who is leading the way for policies encouraging medical research, innovation, and care to benefit Americans as they grow older.



**Chad Worz, PharmD, BCGP**, Chief Executive of the American Society of Consultant Pharmacists (ASCP), accepts the Daniel Perry Founder's Award from Dorothy Ouchida, Member of the Board of Trustees of the ASCP Foundation. This award is presented to an individual or group who is helping to change the paradigm of how we view aging and well-being as we age.



**Congressman Brad Wenstrup (R-OH)** accepts the Distinguished Public Services Award from TC Roberge, Head of Federal Government Affairs for Eli Lilly and Company. This award is presented each year to a Republican member of Congress who is leading the way for policies encouraging medical research, innovation, and care to benefit Americans as they grow older.



**Edwin L. Walker, JD**, Deputy Assistant Secretary for Aging of the Administration on Aging (AoA) within the Administration for Community Living, accepts the Perennial Hero Award from Andrea Masciale, Worldwide Government Affairs & Policy for Johnson & Johnson. This award is presented each year to honor an older individual who is actively contributing to create positive societal change and serves as a role model for people of all ages.



**Henry Buchwald, MD, PhD**, Professor of Surgery and Biomedical Engineering and the Owen H. and Sarah Davidson Wangenstein Chair in Experimental Surgery Emeritus at the University of Minnesota, accepts the Silver Innovator Award from Kim Zimmerman, Senior Vice President and Head of Federal Government Affairs at AdvaMed. This award is presented to an individual who anticipates and embraces the evolution of high-quality research aligned with the needs of older patients.

The event raised a record-breaking \$642,650 for Alliance initiatives.

**View highlights** and **watch a recording of the livestream** online.



## Our Best Shot

The Alliance’s **Our Best Shot** campaign promotes the importance of CDC-recommended vaccines, tackles misinformation and disinformation, and arms older adults with the facts. In 2023, we created **Real Experiences with Vaccine-Preventable Diseases**—a compelling film series featuring adults who share their personal experiences with pneumonia, shingles, respiratory syncytial virus, influenza, and pertussis; **Shingles: What You Need to Know to Avoid a World of Pain**, an animated film on shingles risk factors, symptoms, and prevention through vaccination; an updated **Quick Guide to CDC-Recommended Vaccines for Adults Ages 65+**; and an **infographic factsheet** and GIF campaign that helps combat misinformation and provide the facts about the COVID-19 vaccine. We also continued as co-conveners of the **COVID-19 Vaccine Education and Equity Project (CVEEP)**, which leads important marketing and educational campaigns throughout the year, including the May program, **“Transitioning to Traditional COVID-19 Coverage Post Public Health Emergency;”** and an Alliance-hosted webinar, **“Our Best Shot for a Happy & Healthy Holiday Season,”** in collaboration with USA Boxing and other Olympic Teams, and ASCP.

The Alliance and the American Society of Consultant Pharmacists (ASCP) co-convened a roundtable with more than 45 stakeholders from the public and private sectors to share lessons learned from the COVID-19 pandemic. A resulting white paper, “A Call to Action: Expand & Ensure Access to All Vaccines for Long-Term Care Residents” identified key recommendations needed to sustain and expand access to vaccines at long-term care facilities.

**Visit [AgingResearch.org/OurBestShot](https://AgingResearch.org/OurBestShot).**



## Talk NERDY

Talk NERDY held two training programs in 2023. Clinical Trials Take 2 was held in May on “Randomization, Blinding and Safety in Clinical Trials,” and “Clinical Trials Deep Dive on Explanatory vs. Pragmatic Trials” was held in October. There were approximately 35 student participants in each class taught by Dr. Cary Reid of Weill Cornell and Dr. Doug Landisittel of Indiana University. In the May class, participants learned about the importance and challenges of randomization and blinding, safety issues such as adverse events and serious adverse events and how they are reported to the FDA, and the role of the Data and Safety Monitoring Board and the Institutional Review Board. In October, participants utilized the PRECIS-2 tool to analyze where clinical trials fall on the explanatory to pragmatic spectrum and the advantages and challenges inherent in each for clinical trial participants.

**Visit [AgingResearch.org/NERDY](https://AgingResearch.org/NERDY).**



## Aging In Motion

The Alliance-led **Aging in Motion (AIM)** campaign raises awareness of sarcopenia—a condition involving the progressive loss of skeletal muscle mass and strength that results in functional decline and loss of independence. Our 2023 AIM campaign highlights include: serving on the Steering Committee of the **Global Leadership Initiative on Sarcopenia**—an initiative working on a consensus definition of sarcopenia; publishing the results of an AIM-led survey in the **Journal of the American Geriatrics Society**, which found modest familiarity with sarcopenia and little use of diagnostic criteria among surveyed internists and family medicine physicians; being featured in the opening remarks of the International Conference on Sarcopenia & Frailty Research; raising awareness through an educational PSA campaign viewed by more than 3 million people; and co-authoring a published article in the journal **GeroScience** that describes possible reasons for the lack of new and effective pharmacotherapies to treat sarcopenia.

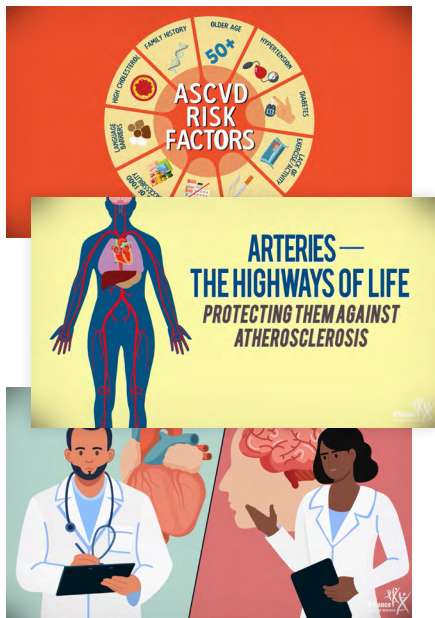
Visit [AgingResearch.org/AginginMotion](https://AgingResearch.org/AginginMotion).



## Age-Related Macular Degeneration

The Alliance updated the popular brochure **Taking a Closer Look At Age-Related Macular Degeneration** to reflect the latest scientific advancements in the field. The brochure takes a “closer look” at AMD by outlining symptoms, risk factors, and prevention. The brochure was downloaded over 4,000 times and garnered over 5,000 page views for all **AMD-related webpages** on the Alliance website.





## ASCVD

The Alliance created an animated educational film, **Arteries— The Highways of Life: Protecting Them Against Atherosclerosis**, on atherosclerotic cardiovascular disease (ASCVD). The film explains how cholesterol and fat from our diet can build up and wreak havoc in our arteries and throughout our bodies, and discusses risk factors, symptoms, prevention, and more. The film has been viewed more than 270,000 times on YouTube and was advertised on digital and streaming radio services producing close to 400,000 true listeners.

## Heart Valve Disease Awareness Day

In its seventh year, the Alliance was joined on **February 22, 2023** by 121 partners dedicated to improving earlier detection and intervention of heart valve disease. The campaign and its partners reached consumers and patients through radio media tours, TV PSAs, op-ed campaigns, press releases, Facebook live expert interviews, large-scale screening events, press events, and more. An event in Louisville, Ky., featuring Congressman Andy Barr (R-KY) having his heart listened to attracted local media attention and a live interview on *Good Morning America Third Hour*. Barr's wife, Carol, passed away as a result of valve disease which led him to sponsor the CAROL Act which increased awareness and funding for valve disease. Through these efforts we were able to reach more than 456,000 listeners through a radio media tour, 67.9 million via TV impressions, 3.5 million in digital impressions, resulting in 1.2 million activations.

A flagship event was held in partnership with the **National Caucus and Center on Black Aging (NCBA)** and **MedStar Heart & Vascular Institute**. The screening and awareness event was held at the NCBA Estates – an independent living community in Washington, D.C. Interns from MedStar offered basic heart screenings including listening to the heart for the murmurs that often accompany valve disease.

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

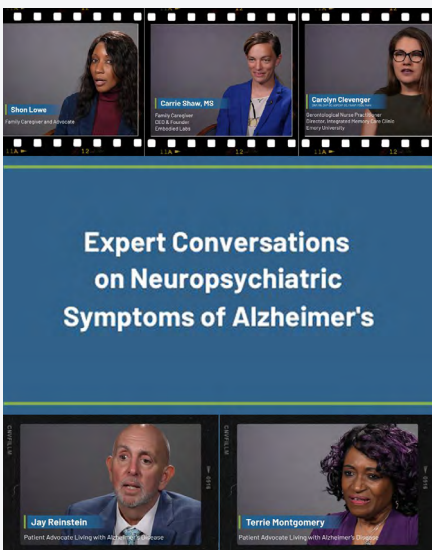




## Accelerate Cures/Treatments for All Dementias

The 16<sup>th</sup> Annual FDA/ACT-AD Allies Meeting, “**Dementia Research Inroads: Where are we now?**” convened experts from academia, pharmaceutical companies, the FDA, and the National Institutes of Health (NIH), as well as members of the Alzheimer’s disease (AD) community. The goal of the meeting was to foster connection and meaningful dialogue around emerging issues and effective treatments for AD and Alzheimer’s Disease-Related Dementias. The discussions highlighted precision medicine, research equity, emerging themes in treatment and prevention, and lessons learned in the regulatory review process. The meeting also featured an informative fireside chat with Dr. Teresa Buracchio, Director of the FDA Center for Neuroscience.

Visit [AgingResearch.org/ACT-AD](https://AgingResearch.org/ACT-AD).



## Shake the Stigma – Neuropsychiatric Symptoms

This year, we produced **Expert Conversations of Neuropsychiatric Symptoms of Alzheimer’s**, a series of films featuring conversations with a clinician, family caregivers, and patient advocates about the neuropsychiatric symptoms (NPS) that accompany Alzheimer’s and other brain diseases and injuries. The films include insights from **Carolyn Clevenger, DNP, RN**, a Gerontological Nurse Practitioner and Director of the Integrated Memory Care Clinic at Emory University; **Carrie Shaw**, CEO and Founder of Embodied Labs who cared for her mother who was living with Alzheimer’s disease; **Shon Lowe**, a patient advocate and family caregiver; and **Jay Reinstein** and **Terrie Montgomery**, patient advocates who are living with Alzheimer’s. The videos and public service announcements directing viewers to the series have been viewed online and on TV and have produced more than 1.8 million impressions and 400,000 views.

## CONGRESS:

**8 IN 10 VOTERS WANT YOU TO REQUIRE MEDICARE TO COVER ALZHEIMER'S TREATMENTS**

### Façade of Evidence:

How Medicare's Coverage with Evidence Development Paradigm Rations Care and Exacerbates Inequity

February 13, 2023



## Coverage Policy Task Force

Building on prior advocacy efforts for Medicare beneficiary access to FDA-approved disease-modifying treatments for Alzheimer's disease, in 2023 the Alliance convened a broader coalition to raise awareness of the increasing use of "coverage with evidence development" (CED) policy by CMS for Medicare beneficiaries. In February, the Alliance released its report, ***Façade of Evidence: How Medicare's Coverage with Evidence Development Paradigm Rations Care and Exacerbates Inequity***, which provides an overview of CED; its deficiencies and harmful consequences; and how CMS' recent application of CED and efforts to reinforce it set a dangerous precedent for future Medicare coverage. The report was released on the first of a two-day meeting of the Medicare Evidence Development and Coverage Advisory Committee (MEDCAC), a federal advisory committee to CMS, where the Alliance and a number of partners **participated**. In August, more than 30 organizations **joined with us on public comments** to outline how proposed CED criteria would harm beneficiaries and be a significant overstep of CMS' authority; and we **submitted a second sign-on comment letter advocating for critical changes** to enhance the transparency and equity of the agency's National Coverage Analysis (NCA) and National Coverage Determination (NCD) processes. In September, a national poll by Lake Research Partners and Public Opinion Strategies—commissioned by the Alliance and partners—found that **eight in ten voters favor requiring Medicare to cover the cost of FDA-approved drugs that can slow the progression of Alzheimer's disease**. While we continue work to end restrictive coverage policy on Alzheimer's treatments, the Alliance celebrated an advocacy victory in October when CMS finally ended its CED policy on Beta Amyloid Positron Emission Tomography (A $\beta$  PET) used to accurately diagnose patients with dementia, Alzheimer's, and other neurodegenerative diseases.



## Project PAUSE

The **Project PAUSE** coalition continued its legislative and regulatory efforts to ensure that **residents in long-term care settings** (e.g., Skilled Nursing Facility, nursing home, assisted-living setting) who have Alzheimer's disease, dementia, and other neuropsychiatric conditions receive high-quality, patient-centered, appropriate care and treatment without facing stigma or coverage barriers. The Alliance in partnership with the American Society for Consultant Pharmacists (ASCP) **responded to a request for comment** on proposed minimum staffing standards for long-term care from the Centers for Medicare and Medicaid Services (CMS). In 2023, Project PAUSE facilitated a bi-partisan Dear Colleague letter from influential members of the House of Representatives to CMS that asked the agency to revisit its nursing home quality measures on antipsychotics, and secured report language in the House of Representatives' Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Fiscal Year 2024 Appropriations Bill for the FDA to conduct an updated evidence review on whether its antipsychotics boxed warning for people with dementia is scientifically supported for the entire class of therapeutics.

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



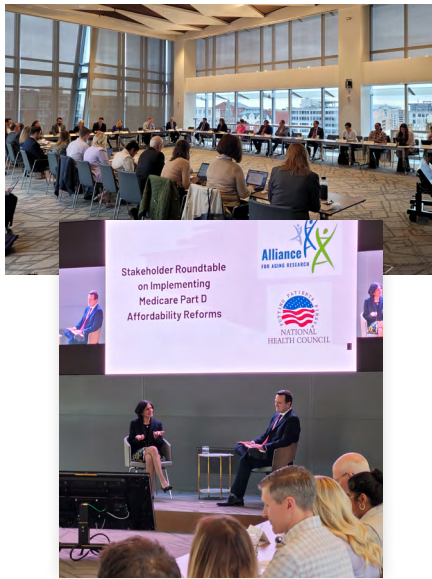
## Impacts of the Inflation Reduction Act

Thanks to the 2022 Inflation Reduction Act (IRA), millions of Americans are seeing savings in their annual healthcare costs. So far, the law has extended Marketplace affordability, capped the cost of insulin at \$35 per month for people with Medicare, eliminated out-of-pocket costs for recommended vaccines, and improved access to affordable prescription drugs. Starting in 2026 for certain Part D drugs and in 2028 for certain Part B drugs, the federal government will exercise new authority to negotiate prices with drug companies. In August, the **Alliance released a statement in response** to CMS' announcement of the first 10 drugs that will be at the center of these landmark negotiations. In **October** and **November**, the Alliance spoke at CMS' Medicare Drug Price Negotiation Program Patient-Focused Listening Sessions and in December, we sponsored an educational **event hosted by The Hill** that highlighted potential unintended access and equity concerns of Medicare direct negotiation. The Alliance has been leading efforts to mitigate the potential unintended consequences that can stem from these new policies, including and most concernedly older adults on the Medicare program facing reduced access to needed medications and therapeutics.



## Step Therapy

Step therapy is a utilization management (UM) tool used by health insurance companies where a patient must "fail first" on a less expensive therapy or course of treatment before being allowed to access the medicine prescribed by their clinician. The 2022 Inflation Reduction Act (IRA) codified changes to Medicare Part D that may incentivize broader application of UM techniques such as step therapy in order to help payers lower expected increases in overall costs. The Alliance is advocating to formalize patient protections in Medicare Part D and stem the use of step therapy that is not backed by clinical guidelines. A policy brief outlining the issue will be released in early 2024.



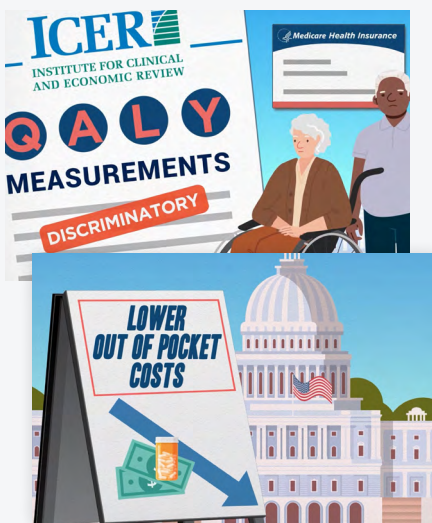
# PROJECT LOOP

LOWER OUT-OF-POCKET COSTS IN MEDICARE PART D NOW

## Prescription Drug Affordability

**Project LOOP** worked closely with the Medicare program in advance of the agency’s implementation of a new \$2,000 annual limit on Medicare beneficiaries’ out-of-pocket (OOP) expenses for Part D prescription drugs, and the ability to pay OOP costs over time in zero-interest payment installments. In May 2023, the Alliance co-hosted a **roundtable** on the implementation of Medicare Part D reforms that brought together a diverse group of patient and consumer advocates, insurers, pharmacy organizations, and biotech organizations to create a common set of **recommendations** for implementation.

The Alliance organized multiple **letters** and meetings to assist CMS in their planning efforts, including a **response co-signed by 62 organizations** encouraging CMS to finalize patient protections and ensure beneficiary access to the payment installment flexibility.



## ICER

Through our **ICERfacts.org campaign**, the Alliance is leading efforts to ensure that older adults and people with disabilities are not discriminated against when insurance companies decide how much a medication or therapeutic is “worth”. Currently, metrics like the Quality Adjusted Life Year (QALY) are being used in federal and private insurance markets. The effort to bring these metrics to the United States is led by a group of economists at the Institute for Clinical and Economic Review (ICER). Their flawed methodology reduces treatment access for older adults. The Alliance is pushing for improved methods and ensured patient access to care. Check out our videos on **QALY’s impact on the Medicare Program** and the **Equal Value of Life Years Gained** metric to learn more.



## Our Podcast: This is Growing Old

In 2023, *This is Growing Old* released its 70th episode. Our engaging guests covered topics spanning alcohol and substance use disorder in older adults, Pride Month, tips for falls prevention at home, and why folks should consider brain donation. Our episodes are catalogued on **YouTube** in addition to all major streaming platforms. An audit of the podcast garnered insightful information to our audiences and allowed us to cover topics that mean the most to our listeners.



## It's Hump Day!

As a mid-year experiment to increase communications with the Alliance Board and stakeholders, we began sharing Hump Day updates – weekly emails sent on Wednesdays that contain bite-sized tidbits of information on our recent work. These feature a lighter side of the news, and the response has been overwhelmingly positive.



## PHAI

The Alliance's Partners in Healthy Aging Innovation (PHAI) includes company members that provide unrestricted support to advance activities related to the Alliance's overall mission and vision. PHAI members participated in the Board of Directors in-person event, which provided opportunities to interact with the Alliance's key staff and leaders in the healthy aging community.



Learn more at [www.AgingResearch.org](http://www.AgingResearch.org).