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# THE AMD EPIDEMIC

## FEBRUARY 2025

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Prepared by  
The American Macular  
Degeneration Foundation



# SUMMARY

**Ask 1:** Fund the National Eye Institute for FY2025 at \$896.5 Million, the same level as FY2024, to preserve and accelerate the development of new treatments.

**Ask 2:** Reverse the 2008 statute that limits Medicare coverage for low vision assistive devices and rehabilitation services, to improve productivity and quality of life for millions of Americans.

**Ask 3:** Support the nation's Vision and Eye Health Surveillance System with \$10 million through the CDC for FY2025 and FY2026, to sufficiently gauge and conduct community-based programs that preserve the sight of Americans.

**Ask 4:** Join the bipartisan Congressional Vision Caucus, whose members are dedicated to strengthening and stimulating a national dialogue around policies related to vision loss, blindness, and visual impairment.

**Ask 5:** Maintain the National Eye Institute as a dedicated institute within the National Institutes of Health (NIH), and insist that any discussions of NIH restructuring include appropriate stakeholder input.



**IN 2022 NATIONAL COST OF LATE-STAGE AMD WAS \$49.1 BILLION. ALL VISION DISORDERS COST \$182 BILLION.**

Total economic impact of all forms of macular degeneration was \$71.5 Billion. Attributed mostly to job loss or job reduction.

Individual cost of total direct medical and pharmaceutical costs, plus lost productivity was estimated at **\$39,301 per person with AMD** in 2021.

The cost in lost quality of life runs much deeper. Loss of independence, isolation, and lost sense of purpose.

AMD is also associated with depression, cognitive decline, early entry into a nursing home and loss of mobility that can lead to overall health declines.



**The burden of AMD vision loss is ALSO** carried by family, friends and other caregivers who sacrifice time and productivity.





## AMD IS ESTIMATED TO AFFECT AS MANY AS 20 MILLION AMERICANS

Age-related macular degeneration (AMD) is the leading cause of vision loss and blindness for Americans 65 and older (CDC).

\*By age 65, the risk for AMD is 1 in 8, and 10,000 baby boomers turn 65 daily.

\*By 75, AMD risk is 1 in 3, and 10,000 baby boomers turn 75 every day.

**52% of registered voters are 50 and older; 24% are 65 and older (Pew Research Center).**

**BY 2050, THE NUMBER OF PEOPLE WITH AMD IS EXPECTED TO DOUBLE!**

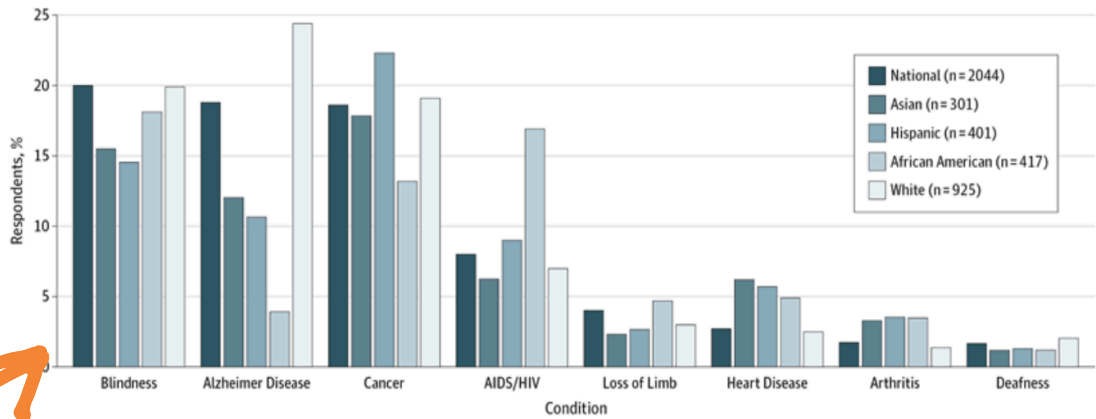




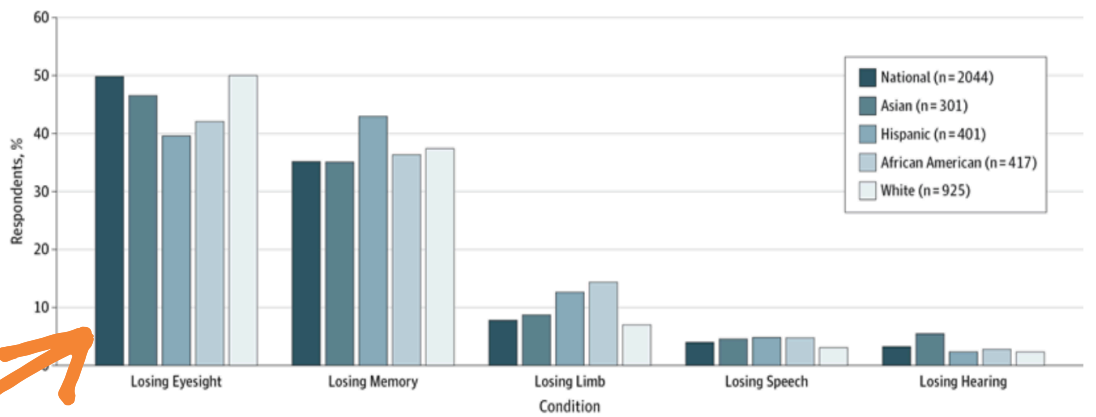
**IN SURVEY AFTER SURVEY...**

**People fear vision loss more than any other condition.**

**Figure 2. Rankings of Worst Conditions**



**Figure 1. Conditions With the Greatest Effect on Day-to-Day Life**





## THE CAUSES AND CURES FOR AGE-RELATED MACULAR DEGENERATION REMAIN UNKNOWN.

However, there have been advances in treatment:

- Longer-lasting eye injections for late stage AMD
- Drugs to slow late-stage dry AMD
- Other potential treatments are in clinical trials

And more breakthroughs are forthcoming. The American Macular Degeneration Foundation is funding investigations into:

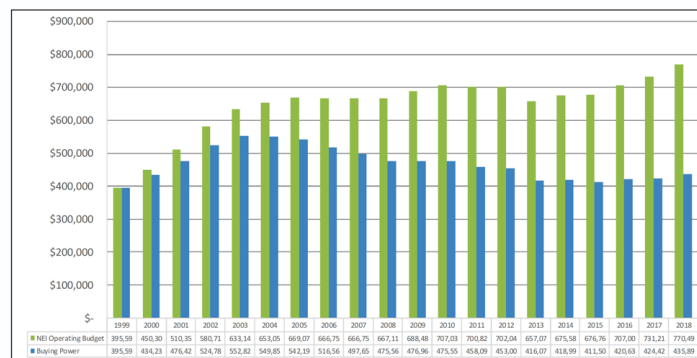
- a one-time gene therapy to halt AMD
- peripheral vision training to better use remaining vision
- the influence of nutrition and the microbiome on AMD

At the National Institutes of Health, **stem cell therapies to preserve or restore sight lost to AMD** are currently in human trials – the result of more than 10 years of research at the NEI. Support from the NEI has also helped researchers develop the new class of drugs recently approved for late dry AMD.



## REQUEST 1: INCREASE VISION RESEARCH SUPPORT

Despite funding increases since 2016, the gap between the NEI's Operating Budget and its actual buying power keeps growing due to biomedical inflation.



**NEI OPERATING BUDGET VS. BUYING POWER SINCE FY 1999 (DOLLARS IN MILLIONS)**

CHART COURTESY OF NAEVR/AEVR

Compounding this gap, the core NEI grant, the ROI, has remained at \$250,000 a year since 1999, meaning critical discovery research scientists have to do a lot more with a lot less.

**AMDF JOINS THE VISION COMMUNITY IN URGING CONGRESS TO APPROVE FY2025 NEI APPROPRIATIONS AT 896.5 MILLION**





## REQUEST 2: ALLOW MEDICARE TO COVER THE COSTS OF LOW VISION ASSISTIVE DEVICES

Since 2008, the Low Vision Aid Exclusion (LVAE) has barred coverage for any low vision aid or device that uses “one or more lens for the primary purpose of aiding vision.”

This policy was intended to curtail costs associated with glasses, but has created a barrier to equitable access for a category of vision-related devices for people with disabling vision loss.

These assistive devices are critical for the physical and mental health of beneficiaries with low vision.

**AMDF URGES CONGRESS TO  
REVERSE THE 2008 STATUTE  
THAT LIMITS MEDICARE  
COVERAGE FOR LOW VISION  
DEVICES AND REHAB SERVICES.**





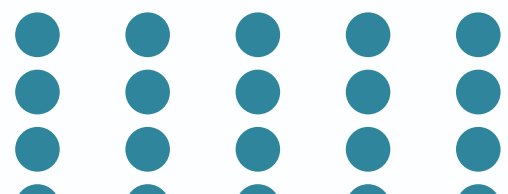


## REQUEST 3: PROTECT FUNDING OF ONGOING EYE HEALTH DATA COLLECTION

The nation's Vision and Eye Health Surveillance System at the CDC has been underfunded for years. Adequate funding will allow optimum deployment of eye health initiatives to address Americans' growing eye health problems.

Both national and local agencies rely on this type of data to more efficiently and effectively implement programs and services that serve constituents with low vision due to AMD or other conditions.

**AMDF URGES CONGRESS TO SUPPORT FY2025 CDC VISION AND EYE HEALTH SURVEILLANCE SYSTEM APPROPRIATIONS AT \$10 MILLION**





## REQUEST 4: JOIN THE BIPARTISAN CONGRESSIONAL VISION CAUCUS

**The Congressional Vision Caucus** is a bipartisan caucus whose members are dedicated to strengthening and stimulating a national dialogue around policies related to vision loss, blindness, and visual impairments or disabilities.

With the concerning increase of the vision-stealing disease of age-related macular degeneration, vision loss will become more of an issue for your aging constituents. Be ahead of the challenges by joining important discussions.

**AMDF URGES YOU TO  
CONSIDER BECOMING A  
MEMBER OF THE VISION  
CAUCUS**





## REQUEST 5: MAINTAIN THE NATIONAL EYE INSTITUTE (NEI) AS A DEDICATED INSTITUTE

The National Eye Institute (NEI) is the most important source of funding for all of vision research in the U.S. and globally.

The proposal from a committee in the House of Representatives to collapse the National Institutes of Health's (NIH) 27 institutes into 15 institutes includes eliminating the NEI and leaving its work to a general brain and neuroscience-focused institute.

If the NEI is eliminated, there will be less research into eye diseases such as age-related macular degeneration, corneal diseases, dry eye, glaucoma, diabetic eye disease, inherited retinal diseases and more, and patients – your constituents – will ultimately be the ones to suffer.

**AMDF URGES YOU TO  
MAINTAIN THE NEI AS A  
DEDICATED INSTITUTE WITHIN  
THE NATIONAL INSTITUTES OF  
HEALTH (NIH)**

