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THE AMD EPIDEMIC

FEBRUARY 2026

Prepared by
The American Macular
Degeneration Foundation

WHAT WE ARE ASKING

Ask 1: Increase NEI funding to \$1 billion in FY27 to match growing public health needs.

Ask 2: Support access to low vision assistive devices and services by urging the Centers for Medicare and Medicaid Services (CMS) to rescind the Medicare “Low Vision Aid Exclusion” at 42 C.F.R. § 411.15(b).

Ask 3: Protect Vision and Eye Health Funding in FY27 by supporting the CDC Vision Health Initiative FY27 appropriations package at \$6.5 million.

Ask 4: Reject any proposed consolidation of the National Eye Institute (NEI) by maintaining the NEI as a dedicated institute within NIH in the FY27 appropriations bill.

Ask 5: 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.



**IN 2022 NATIONAL COST
OF LATE-STAGE AMD WAS
\$49.1 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 early entry 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

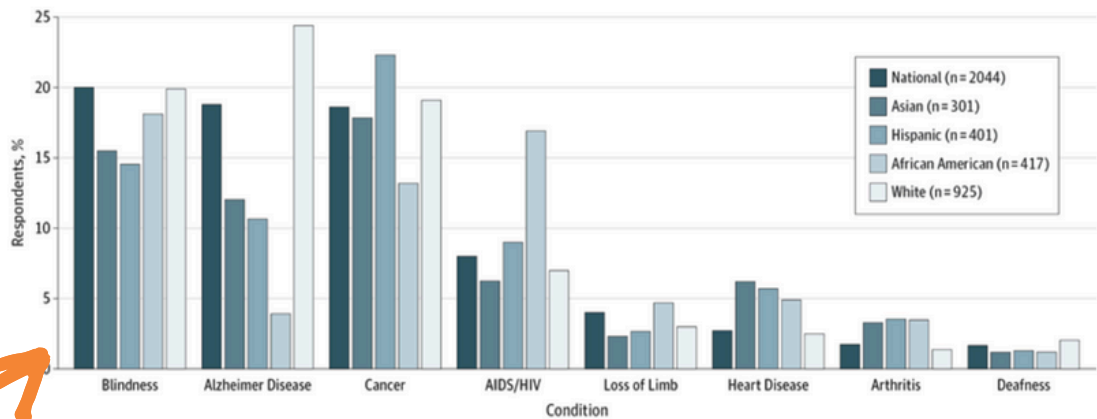
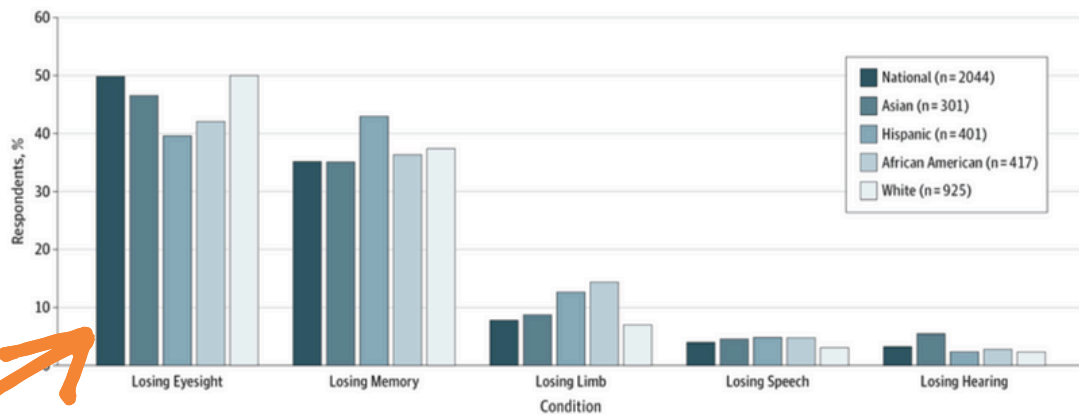


Figure 1. Conditions With the Greatest Effect on Day-to-Day Life





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 are now available
- Recent FDA approval of light therapy to treat intermediate AMD

And more breakthroughs are forthcoming. The American Macular Degeneration Foundation has funded investigations into:

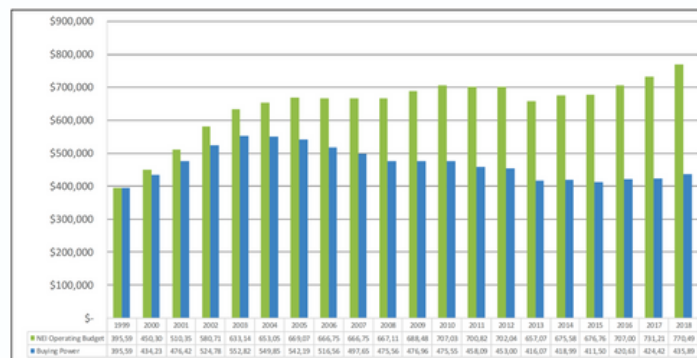
- a one-time gene therapy to halt AMD and Stargardt that is performing well
- brain training to better use remaining vision
- the influence of nutrition and the microbiome on AMD

At the National Institutes of Health, **stem cell therapies to preserve or restore sight lost to AMD** are in human trials, new imaging techniques have been developed to help in AMD diagnosis, and new treatment targets have been identified.



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 NAEV/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 FY2027 NEI APPROPRIATIONS AT \$1 BILLION





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
HAVE THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES (CMS) RESCIND THE
MEDICARE “LOW VISION AID
EXCLUSION” AT 42 C.F.R. §
411.15(B).**



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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 FY2027 CDC VISION
AND EYE HEALTH
SURVEILLANCE SYSTEM
APPROPRIATIONS AT \$6.5
MILLION**





REQUEST 4: 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.

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)**



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REQUEST 5: 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**

