

NAEVR
AEVR

RPB Convening Federal Funding Update



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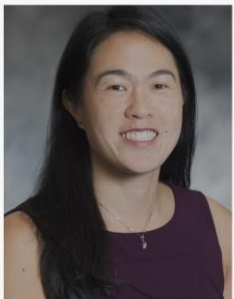
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OUR FOCUS

- Advocate for robust funding and policies that advance vision research, accelerate discovery, and promote access, improving patient outcomes and paving the way for a future free from vision loss.



OUR FOCUS



SUPPORT NEI AND VISION RESEARCH

We can't be everything for NIH on our own, but have to be everything for NEI



COLLABORATE WITH COALITION PARTNERS ON BROADER NIH CHALLENGES

Without a strong NIH, NEI may not exist



TARGET OUR PRIORITIES TO ENSURE A ROBUSTLY FUNDED, DEDICATED NEI

Grasstops

Targeting key committees and caucuses

Targeting swing votes

Targeting relationships and connections



PRIORITIZE VISION RESEARCH AS A NATIONAL PRIORITY

Grassroots

#SeeWhatMatters

#VisionMatters

#VisionResearch

FY26 FUNDING STATUS:

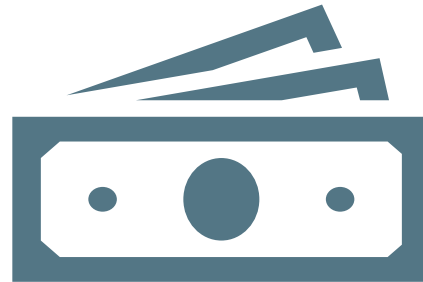
	FY22 Final	FY23 Final	FY24 Final	FY25 Final	FY26 NAEVR Request
NIH	\$44.96 B +4.72%	\$47.46 B +5.6%	\$47.08 B -0.8%	\$47.08 B +0%	\$51 B +6.4% Over FY25
NEI	\$863.9 M +3.4%	\$896.55 M +3.8%	\$896.55 M +0%	\$896.55 M +0%	\$1 B +11.5% Over FY25 Maintain NEI as an independent institute
DOD VRP	\$20 M +0%	\$20 M +0%	\$20 M +0%	\$0 -100%	Restore funding to \$30 M** +100%

- The FY23 budget included funding for ARPA-H within NIH at \$1.5 B and was level-funded in FY24. The FY25 Senate Bill includes level funding at \$1.5 B, the House bill reduces ARPA-H to \$500 M
- The Fiscal Responsibility Act of 2023 (Debt Ceiling Agreement) put caps on federal spending for FY24 and FY25. A new debt limit increase is needed in 2025 to avoid default and may result in additional restrictions on spending.
- In FY23, BRAIN Initiative funding was \$680M. Due to the expiration of 21st Century Cures funding, that was reduced to \$402 M in FY24 and was reduced further to \$321M in FY25. The Senate sought to restore the 21st Century Cures funding in FY25 but was unsuccessful in the CR.
- **Seeking supplemental funding to restore FY25 funding before September in addition to FY26 ask

FEDERAL FUNDING STATUS



Government is operating under a full year Continuing Resolution (CR) passed on March 13, 2025 until September 30, 2025



Funding largely kept level for NIH:

Elimination of 23 funded programs within the Defense Health Research portfolio, including Vision

Expiration of \$91 M in BRAIN Initiative from 21st Century Cures in addition to the \$278 M that expired in FY24

Risks remain due to debt limit increase and reconciliation



Advocating for stable NEI and NIH funding without the proposed 15% indirect cap in FY26, and either supplemental funding for FY25 or restoring funding in FY26 for VRP

CURRENT NIH AND NEI CHALLENGES



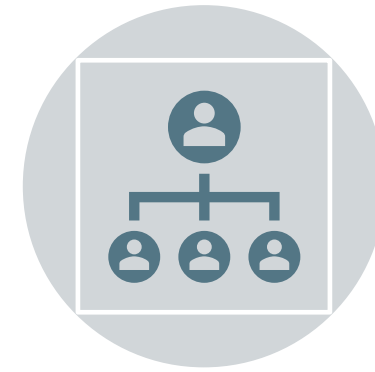
Funding freezes



Proposed 15% indirect cost cap (F&A costs)



Legal challenges to funding freezes and 15% cap remain unresolved



With restructurings, consolidations, and reductions in force occurring across agencies, we could see impacts on internal and external operations

FEDERAL FUNDING FREEZE THREATS

The Administration imposed a funding freeze affecting agencies including NIH in January, halting travel, spending, and grant review meetings, resulting in what is estimated to be approximately \$1.5 billion in stalled NIH grant applications.

■ **Impacts:**

- ❑ Grant Review Meetings Suspended: Essential review sessions halted. New requirement for Center for Scientific Review to conduct all first-level peer reviews moving forward
- ❑ Stalled Grant Applications: An estimated 16,000 grant proposals have been delayed.
- ❑ To date, ~150 grants have been canceled (typically about 20 are canceled in a calendar year), and more are anticipated in the coming weeks.
- ❑ Disruptions in Research: Funding uncertainties affecting ongoing and future studies.

■ **Congressional and Legal Interventions:**

- ❑ Lawsuits Filed: Legal action challenging the freeze. Two judges blocked the freeze but the Administration continues to delay.
- ❑ Congressional Advocacy: Push to reinstate research funding and grant approvals.
- ❑ Partial Lifting of Freeze: Some NIH operations resuming, but uncertainties remain on timelines and decisions.

■ **Current Status:**

- ❑ Partial Lifting of Freeze: NIH has reportedly started taking steps to move forward, but delays persist with most advisory councils not set to meet.
- ❑ Future Uncertainty: No clear timeline for full restoration of funding or when councils will be able to proceed.
- ❑ Monitoring Congressional and Court Actions: Potential legislative or legal pressure for full funding reinstatement.

NIH 15% INDIRECT RATE CAP

On February 7, the Administration issued a notice that would impose a 15% cap on indirect rates on all existing and future NIH grants that would have gone into effect on February 10.

■ **Advocacy community response:**

- Decisively pushing back and raising awareness about the threat these caps would pose
- Bipartisan concern with the policy shift and the impact it would have nationwide

■ **Legal response:**

- Lawsuits were filed by 22 states and major research institutions arguing the cap violates the Administrative Procedures Act (APA) , which requires notice and comment periods on significant policy shifts.
- On February 10, a federal judge issued a Temporary Restraining Order (TRO) blocking the implementation.
- On February 21, the TRO was extended.
- Reports indicate that a decision from the court could come as early as the next week or two.

■ **Implications:**

- We recognize the significant impact this would have and are urging Congressional intervention if necessary

CONSOLIDATION THREATS AND NEI

Currently, there is no active consolidation plan to implement for NIH.

What we've been told so far:

- Consolidation as proposed in 2024 is unlikely to proceed for FY25.
 - “The appropriations bill was meant to drive a stake in the ground to say we need to have these difficult conversations to restructure because they arise every decade or two and nothing substantial has changed.”
- NAEVR focused on maintaining NEI as a standalone and dedicated institute
 - Offices continue to express support for NIH, but continue to focus more on “accountability, transparency, and reporting” in addition to conversations that persist around consolidation or restructuring.
- Advocating against the potential for administrative restructuring without congressional engagement
 - The Trump Administration has already eliminated/significantly altered existing federal agencies that have appropriations funding from Congress, without sufficient blowback to stop them, this could be a risk for NIH and other agencies inside HHS
- Restructuring continues to be of interest, particularly with Republican offices
 - Reconvening of Scientific Management Review Board (SMRB) in November 2024 with report expected in 2025



CONTINUED CHALLENGES

- **Timing of council meetings to review and approve grants, when will the Center for Scientific Review begin taking over first peer review?**
- **Threats of 15% indirect cap**
- **Threats persist around NIH consolidation, including the NEI**
- Debt ceiling negotiations may include more spending cap restrictions
- Government spending cuts are proving to be a priority:
 - Budget Reconciliation priorities (target of \$2 trillion spending cuts over ten years to offset proposed tax cuts of \$4.5 trillion)
- Executive orders and actions
- Restructuring of grant mechanisms and payments – shifts to states?



PREPARING & RESPONDING TO POSSIBLE SCENARIOS

- Republicans could push through NIH structural reforms in Congress (unlikely at this time).
- Hearings and testimony from stakeholders could be sought as Congress considers reforms.
- The Administration may make structural or policy changes.
- Congress may request that the new NIH Director submit recommendations for NIH reforms for Congressional consideration (Scientific Management Review Board reconvened)
- Congress and the Administration could cut funding broadly.
- Congress could consider "Project 2025" policy recommendations and explore restructuring, policy changes, and even redistributing NIH funding through block grants to states.





WHAT COULD THE CURRENT LANDSCAPE MEAN FOR RESEARCH AND RESEARCHERS?

- Less funding available (even level funding of an Institute is a cut due to inflation)
- Federal funding freeze resulting in canceled grants, delays in grants, staff hiring, etc.
- Indirect caps could shutter labs and further reduce research at academic institutions
- Downstream NIH funding gaps
- Consolidation/restructuring is likely to dilute the existing focus on research areas (like vision)
- Block grants could fundamentally change the research funding landscape
- Fewer scientists would be able to pursue careers in academic research
- Potential for research talent leaving the US to places like China and Europe as they invest more in research
- Potential for a lost generation of scientists in the United States

WHAT CAN WE DO, WHAT DO WE NEED TO DO?

- Engage with partners in the advocacy space to leverage impact
- Solicit stories and experiences from researchers, clinicians, and patients
 - The value of vision
 - The value and impact of research
 - The improvements to care
- Communicate and engage with policymakers – engage networks effectively with partners
- Support career development for researchers (communications and advocacy training)
- Share examples of the value of research investment and ROI
- Enhance foundation communications regarding indirect rates
- Lead and enhance the conversation with partners and the public around making vision loss a national priority



IF YOU'RE
NOT AT THE
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MENU



WHAT WORKS AND WHAT DOESN'T?

■ WORKS

- Personal stories from patients and caregivers
- Clear connections between research and real-world breakthroughs
- Direct and concise messaging
- Building coalitions/partners
- Leveraging communications and social platforms
- Data-driven arguments
- Grassroots efforts
- Grasstops efforts

■ DOESN'T WORK

- Overly technical or scientific language
- Focusing on research without tying to the patient impact
- One-off efforts without a sustained strategy
- Lack of a clear or unified message
- Assuming scientific merit is all that matters
- Minimal patient or community involvement in advocacy efforts
- Failure to demonstrate ROI
- Passive communication

NAEVR ACTIONS & ONGOING EFFORTS

- Developed a sign-on letter for NEI and VRP programs to be sent in April
- Provided public statements on NIH indirect caps and consolidation concerns both as an organization and with coalition partners (over 600 organizations signed onto Research!America letter)
- Bringing together key stakeholders to discuss coordinated strategies and messaging opportunities
- Grassroots letters:
 - Updated Consolidation letter to push back on NEI Consolidation threats (over 6,000 letters sent in)
 - Developed and initiated a grassroots letter regarding NIH indirect caps (over 1,500 letters sent in)
 - Provided Contact Congress Letters for partners to amplify vision research community concerns within their networks
- **Developing a “grasstops” program to engage leaders in vision care and vision research****
 - Clinicians, researchers, and patients
- **Enhancing training efforts for researchers to be engaged in advocacy****
- Updated website to include fact sheets and resources for partners
 - Advocacy requests with justification for FY25 and FY26
 - Talking points supporting vision research
 - Fact sheets highlighting projected growth in prevalence
 - Complete set of state-based fact sheets with economic burden, some disease incidence, and NEI funding levels for each state

NAEVR ACTIONS & ONGOING EFFORTS

- **Targeting key Congressional offices (moderate Republicans, key caucuses, key committees)**
 - Caucuses: Vision Caucus, Diabetes Caucus, Research and Development Caucus, Doctors Caucus, Public Health, Problem Solvers, etc.
 - Committees: House and Senate Appropriations, House Energy & Commerce, House Ways and Means, Senate Finance, Senate Health Education Labor & Pensions
- Reaching out to Administration Officials and Agencies like the Office of Management and Budget (OMB)
- **Working to develop a campaign to engage grassroots and grassroots in advocacy and awareness efforts promoting the importance of vision and the value of vision research**
- Launching a blog to provide more frequent updates on activities, and provide FAQ updates regarding NIH/NEI issues as they arise
- Congressional briefings with speakers targeting key districts
- Asking for stories and experiences from the community to share with Congressional offices regarding policy impacts.

AEVR CONGRESSIONAL BRIEFINGS

■ 2024 Briefings

- AMD Briefing – February
- Rare Eye Disease Briefing – May
- Dry Eye Disease Briefing – July
- NEI Accomplishments Briefing – September
- Thyroid Eye Briefing – November
- Myopia Briefing - December

■ 2025 Briefings:

- AMD Briefing – February
- Glaucoma Briefing – March
- Rare Eye Disease Briefing - May
- Dry Eye Disease Briefing – July
- Diabetic Eye Disease Briefing – September
- Myopia Briefing - October



EMERGING VISION SCIENTIST PROGRAM

- 2024
 - 34 EVS participants from 17 states
 - Congressional Poster Reception
 - Meet with Policymakers
- 2025
 - Planning for 40 participants
 - Training:
 - Communicating research to a non-research audience
 - Advocate for vision research
- **The EVS program is supported by a grant from Research to Prevent Blindness**



WHAT CAN YOU DO?

- Join the Alliances as an organizational or institutional Member



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- Join the Alliances as an Individual Member/donor (available next month)



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- Join the Alliances as an Individual Member/donor (available next month)
- Advocate
 - Send a letter from NAEVR's website, get involved

**Send a letter to your
Congressional leaders:**



WHAT CAN YOU DO?

- **Join the Alliances as an organizational or institutional Member**
- **Join the Alliances as an Individual Member/donor (available next month)**
- **Advocate**
 - Send a letter from NAEVR's website, get involved
- **Encourage nominations for the Emerging Vision Scientist Program**

Nominate faculty and early career researchers to apply to our Emerging Vision Scientist Program:



WHAT CAN YOU DO?

- **Join the Alliances as an organizational or institutional Member**
- **Join the Alliances as an Individual Member/donor (available next month)**
- Advocate
 - Send a letter from NAEVR's website, get involved
- Encourage nominations for the Emerging Vision Scientist Program
- Sign up for our newsletter and spread the word

**Sign up for our
monthly updates:**



WHAT CAN YOU DO?

- Join the Alliances as an organizational or institutional Member
- Join the Alliances as an Individual Member/donor
- Advocate
 - Send a letter from NAEVR's website, get involved
- Encourage nominations for the Emerging Vision Scientist Program
- Sign up for our newsletter and spread the word
- Follow NAEVR/AEVR on social media and sign up for our monthly updates

Follow us:

eyerresearch.org

Twitter / X – [@NAEVRAdvocacy](https://twitter.com/NAEVRAdvocacy)

Facebook – facebook.com/NAEVR

LinkedIn – linkedin.com/company/national-alliance-for-eye-and-vision-research/



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