

NAEVR
AEVR

ARVO Town Hall: Vision Research Funding

Board of Directors



Steve Feldon, MD, MBA
[President](#)



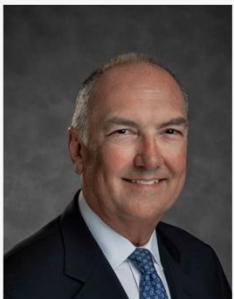
Gregory Skuta, MD
[Vice President](#)



**Kelly Nichols, OD, MPH, PhD,
FAAO**
[Treasurer](#)



Judy Kim, MD
[Secretary](#)



Eduardo Alfonso, MD



T. Rowan Candy



Marissa Goldberg



Brian Hoffland, PhD



Joan O'Brien, MD



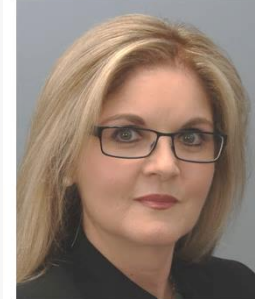
**Grace Prakalapakorn, MD, MPH,
PhD**



Rajesh Rajpal, MD



Michael Robinson, MD



Iris Rush, CAE



Paul Sternberg Jr., MD



INTRODUCTION

- Welcome
- The “Alliances” AEVR/NAEVR
 - Education and Advocacy in support of Eye & Vision Research
 - Created by ARVO, AUPO, and AAO
 - 50+ partnering organizations
- Current challenges to research
- What we are doing and how you can help
- Introducing Dan Ignaszewski, Executive Director AEVR/NAEVR

Dan Ignaszewski

Executive Director

A seasoned leader in public policy and nonprofit strategy, Dan has championed federal support for vision research by building coalitions across government, advocacy, and industry. With a background in healthcare advocacy and policy, including leadership at the Amputee Coalition, he offers a track record of advancing legislation, strengthening stakeholder engagement, and driving impactful, mission-focused initiatives.



MISSION:

- 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, but must 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 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
NIH	\$45.0 B +4.72%	\$47.5 B +5.6%	\$47.1 B -0.8%	\$47.1 B +0%
NEI	\$863.9 M +3.4%	\$896.55 M +3.8%	\$896.55 M +0%	\$896.55 M +0%
DOD VRP	\$20 M +0%	\$20 M +0%	\$20 M +0%	\$0 -100%

Trump Administration FY26 Request
\$27 B -37% Below FY25
Consolidate NEI into a Neuroscience and Brain Institute with NIDCR and NINDS – cuts likely to be near 37%, but cuts may not be distributed equally among IC's
ARPA-H maintained, level unknown 15% Indirect, total of 5 institutes

FY26 NAEVR Request
\$51 B +6.4% Over FY25
\$1 B +11.5% Over FY25 Maintain NEI as an independent institute
Restore funding to \$30 M** +100%

- The FY23 budget included funding for ARPA-H within NIH at \$1.5B and was level-funded in FY24 and FY25.
- 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, which was reduced to \$402M in FY24 and was further reduced 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 requesting restoration in FY26 ask.**

FEDERAL FUNDING STATUS



Congress 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 \$91M in BRAIN Initiative from 21st Century Cures in addition to the \$278M 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



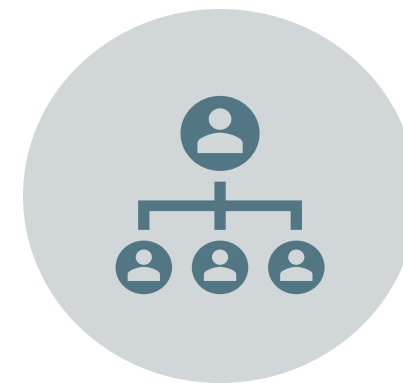
Funding Freezes
Grant Delays
Grant Cancelations



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



Legal challenges to
funding freezes and
15% cap remain
unresolved
(pending appeals)



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

FEDERAL FUNDING FREEZE THREATS

NIH funding freeze imposed in January halted travel, spending, and grant reviews—delaying ~\$1.5B in grants.

■ Impacts:

- ❑ **Peer Review Disrupted:** Key grant review meetings suspended; new centralized review mandate added.
- ❑ **Delays:** ~16,000 grant applications stalled.
- ❑ **Cancellations:** Nearly 1,000 grants canceled vs. ~20 in a typical year.
- ❑ **Research Halted:** Funding gaps threaten ongoing and future studies.

■ Congressional and Legal Interventions:

- ❑ **Lawsuits:** Courts blocked freeze, but delays continue.
- ❑ **Congressional Push:** Lawmakers pushing to reinstate funding.
- ❑ **Partial Relief:** Some NIH activity resumed; outlook unclear.

■ Current Status:

- ❑ **Uncertainty Remains:** Advisory councils meeting, but fund allocation unclear.
- ❑ **Future at Risk:** No timeline for full reinstatement; and significant concerns around **impoundment**.
- ❑ **Ongoing Monitoring:** Legal and legislative developments expected.

NIH 15% INDIRECT RATE CAP

Policy Announcement: On Feb. 7, the Administration proposed a 15% cap on indirect costs for all NIH grants, effective Feb. 10.

- **Advocacy Response:**

- Broad pushback from the research and advocacy community.
- Bipartisan concern over national impact.

- **Legal response:**

- 22 states and institutions sued, citing lack of required public comment.
- Federal judge issued a TRO on Feb. 10; extended Feb. 21.
- Permanent injunction issued Apr. 4; appeal expected.

- **Implications:**

- Cap would severely impact research institutions.
- Congressional intervention may be necessary.

CONSOLIDATION THREATS AND NEI

Current Status: No active consolidation plan in Congress for FY26.

President's Proposal: FY26 budget proposes merging 27 NIH institutes into 5.

What we Know:

- FY26 consolidation had been deemed unlikely prior to Administration's Budget Request, but restructuring conversations continue and may pivot.
- Quote: "Appropriations bill signals it's time for tough restructuring talks."
"The FY25 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's position:** Strongly advocates to keep NEI independent and standalone.
- **Hill Feedback:**
 - ❑ Broad support for NIH, but focused on "accountability, transparency, and reporting" in addition to talk about consolidation or restructuring.
- **Concerns:**

Advocating against the potential for administrative restructuring without congressional engagement

 - ❑ Admin may act without Congress, as seen with other agencies.
 - ❑ GOP interest in restructuring remains strong.
 - ❑ Reconvening of Scientific Management Review Board (SMRB) Nov. 2024; report expected 2025





PROPOSED RESTRUCTURING IN PRESIDENT'S BUDGET

- National Institute on Body Systems Research
- National Institute on Neuroscience and Brain Research
- National Institute of General Medical Sciences
- National Institute of Disability Related Research
- National Institute on Behavioral Health
- +
- ARPA-H?

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 remain
- Threats persist around NIH consolidation, including the NEI
- Proposed funding cuts (37% reduction at NIH in the President's budget request)
- Debt ceiling negotiations may include more spending cap restrictions for FY26 and future years
- 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 may push NIH reforms in Congress (but Senate likely blocks major changes for now with 60-vote threshold).
- Hearings and stakeholder testimony could shape Congressional reform efforts.
- The Administration may implement changes without awaiting Congressional approval or direction.
- Congress could request reform recommendations from the new NIH Director (Scientific Management Review Board input expected).
- Broad NIH funding cuts remain a risk.
- “Project 2025” proposals could prompt restructuring, policy shifts, or block grant models for NIH funding.



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).
- Low prioritization of vision if consolidated in a broader Neuroscience and Brain Institute.
- Block grants could fundamentally change the research funding landscape.
- Fewer scientists able to pursue careers in academic research.
- Potential for research talent leaving the U.S. to China, Canada, Europe, and Asia as they invest more in research.
- Potential for a lost generation of scientists within the U.S.

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

- Engage with advocacy partners like NAEVR to amplify impact.
- **Solicit stories and experiences from researchers, clinicians, and patients – meet, write, and call your members of Congress**
 - Highlight the value of vision, research, and improved care outcomes.
- Engage policymakers and networks through coordinated outreach.
- Support researcher development (communications and advocacy training).
- Share examples of the value of research investment and ROI.
- Enhance foundation communications regarding indirect rates/F&A costs.
- Lead public dialogue on making vision loss a national health priority.



**If You're Not
at the Table
You're on
the 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 May
- 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
 - Completed 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 grastops 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 - June
- 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 at least 40 participants
- ❑ Training:
 - Communicating research to a non-research audience
 - Advocate for vision research

- **Supported by a grant from Research to Prevent Blindness**



WHAT CAN YOU DO?

- Join the **Alliances** as an **organizational** or **institutional Member**



WHAT CAN YOU DO?

- Join the **Alliances** as an **organizational or institutional Member**
- Join the **Alliances** as an **Individual Member** (available next month)



WHAT CAN YOU DO?

- **Join the Alliances as an organizational or institutional Member**
- **Join the Alliances as an Individual Member**
- **Advocate**
 - Send a letter from NAEVR's website

**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**
- Advocate
 - Send a letter from NAEVR's website
- 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**
- Advocate
 - Send a letter from NAEVR's website
- Encourage nominations for the Emerging Vision Scientist Program
- 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**
- Advocate
 - Send a letter from NAEVR's website
- Encourage nominations for the Emerging Vision Scientist Program
- 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/

QUESTIONS AND CONTACT INFORMATION



Dan Ignaszewski

Executive Director

202-742-1885

dan@eyersearch.org



Judy Hill

Director of Communications & Events

240-351-3413

judy@eyersearch.org