

President's Message

As we reflect on the past few months, I want to extend my deepest gratitude to each of you for your unwavering commitment to advancing vision research through the National Alliance for Eye and Vision Research (NAEVR) and the Alliance for Eye and Vision Research (AEVR). Your support has been instrumental in our collective efforts to advocate for vision research funding, even amidst an increasingly challenging federal budget environment.

This summer, and with your help, NAEVR played a crucial role in pushing back against the Energy & Commerce Committee's NIH Reform Report. The recommendations within the report posed significant risks to the dedicated funding and structure of the National Eye Institute (NEI). Our prompt and strategic response was vital in ensuring that the value of a focused, well-funded NEI continues to be recognized. Through coordinated advocacy and the mobilization of our members, we made it clear to policymakers that vision research must remain a top priority.

Our Alliances continue to lead the charge in advocating for the essential role that vision research plays in improving public health. From meeting with key legislators to educating new members of Congress, we have tirelessly championed the cause of sustaining and increasing NEI funding. As we prepare for the FY25 budget discussions, our work is more important than ever. The NEI's research is critical to addressing the growing burden of eye diseases, and we must ensure that it receives the resources it needs to continue making groundbreaking discoveries.

Looking ahead, we are expanding our strategic initiatives to ensure that our voice remains

strong and influential. We are enhancing our communication efforts, strengthening partnerships, and engaging new stakeholders. Additionally, we are inviting all members and supporters to join us in these advocacy efforts. Your involvement is crucial as we continue to educate policymakers on the importance of a dedicated NEI and the need for sustained investment in vision research.

If you are not yet a member of NAEVR/AEVR, I encourage you to join us. Your membership not only supports our advocacy efforts but also allows us to expand our educational programs, such as the Emerging Vision Scientist program. Together, we can ensure that vision research remains a priority for our nation's leaders and that the NEI is equipped to meet the challenges ahead.

Thank you for your ongoing support and for standing with in this critical work. We look forward to continuing this journey together to advance vision research and protect the future of eye health.

Sincerely,

Steven Feldon, MD, MBA

President, Board of Directors
NAEVR/AEVR



NAEVR Leads the Charge: Advocating for NEI’s Independence Amid Legislative Challenges

	FY21 Final	FY22 Final	FY23 Final	FY24 Final	FY25 NAEVR Request	FY25 President's Budget	FY25 House Budget	FY25 Senate Budget
NIH	\$42.93 B +3%	\$44.96 B +4.72%	\$47.46 B +5.6%	\$47.08 B -0.8%	\$51.3 B +9.0% Over FY2023	\$50.1 B +6.4% Over FY24	\$48.6 B +3.2% Over FY24	\$48.8 B +3.7% Over FY24
NEI	\$835.71 M +1.4%	\$863.9 M +3.4%	\$896.55 M +3.8%	\$896.55 M +0%	\$1B +11.5% Over FY2024	\$898.82 M +0.3% Over FY2024	Level funded but proposed consolidation into a new Institute on Neuroscience and Brain Research	\$896.55 M +0% Over FY2024
DOD VRP	\$20 M +0%	\$20 M +0%	\$20 M +0%	\$20 M +0%	\$30 M +50%	N/A	\$20 M +0%	N/A

- 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
- The Senate bill restores funding to the BRAIN Initiative in the amount of \$359 M, comparable to the FY23 level prior to the expiration of funding in the 21st Century Cures Act

NAEVR has been actively engaged in advocacy efforts to request increased funding for the National Eye Institute (NEI) and to protect its role as a dedicated institute within the National Institutes of Health (NIH) in the face of significant legislative challenges this summer. A proposal from the House Energy & Commerce (E&C) Committee to restructure the NIH has raised serious concerns within the vision research community. This proposal, released in June, includes a recommendation to consolidate the NEI with other institutes to form a new “Institute on Neuroscience and Brain Research.” Such a consolidation could undermine the focused research efforts that have been crucial in advancing eye health, threatening decades of progress.

In response to this proposal, NAEVR immediately launched a robust campaign to push back against the proposed changes. The recommendation to reduce the number of NIH Institutes and Centers from 27 to 15, including merging the NEI with other institutes, presents a significant threat to the progress made in vision research. Recognizing the urgency, NAEVR quickly engaged stakeholders across the vision and biomedical research communities to coordinate a strategic response. These efforts included building a coalition with organizations such as the American Dental Association, the American Association of Neurological Surgeons, and the Society for Neuroscience, all of whom oppose the proposed restructuring.

Throughout the summer, NAEVR staff held meetings with multiple congressional offices to express concerns about the impact of the E&C report on vision research. These discussions were instrumental in shaping a unified response to the proposed NIH changes. To ensure the voice of the vision research community was heard, NAEVR also focused on strategic communications. On July 3, an update was sent to members and stakeholders outlining a comprehensive strategy for opposing the proposed changes. This included plans to develop both individual and organizational response letters to amplify the collective voice of the community. NAEVR worked closely with the Coalition for Health Funding, resulting in a broad letter sent to Congress on July 9, highlighting widespread opposition to the NIH consolidation proposals.

These efforts culminated in the submission of formal comments to the House E&C Committee’s NIH Reform inbox by the August 16 deadline. NAEVR’s comments emphasized the critical need to preserve the NEI as a standalone institute, which is essential for continued advancements in vision research. Over 90 organizations supported NAEVR’s organizational sign-on letter, and more than 5,000 individual letters from the vision research community were sent to Congress before the August 16 deadline, demonstrating widespread support for maintaining NEI’s independent status.

(cont’d) As the FY25 budget process unfolds, the situation remains fluid. The House Labor, Health and Human Services (LHHS) Appropriations Subcommittee included the NIH consolidation proposal in its FY25 appropriations bill, which passed through subcommittee markup but faces uncertainty in the full committee and on the House floor. In contrast, the Senate’s LHHS Appropriations bill, passed with bipartisan support on August 1, included level funding for NEI and maintained the current structure of the NIH, providing a more favorable baseline for negotiations. NAEVR, along with its coalition partners, remains vigilant in advocating against the consolidation and for the necessary funding increases to support the NEI.

The importance of NAEVR’s advocacy efforts cannot be overstated. The organization has consistently highlighted the risks that legislative changes pose to vision research and has worked tirelessly to ensure that policymakers understand

the value of maintaining a standalone NEI. Although the proposal to consolidate the NEI is unlikely to advance this year, NAEVR is preparing advocacy messaging and efforts this fall with an eye on the upcoming elections. Following the elections, NAEVR will update and revise its strategies based on the outcomes and their projected impact on the NIH Reform proposal.

NAEVR’s proactive stance and the collective efforts of the vision research community will be crucial in ensuring that the NEI remains a priority for our nation’s leaders. Continued involvement from all members of the vision research community is essential to maintaining momentum and protecting the future of vision research. NAEVR encourages everyone to stay informed and engaged in these efforts. For more information on how you can NAEVR’s advocacy, follow us on social media and contact us at info@eyersearch.org to inquire about membership opportunities.

ARVO Annual Meeting: A Hub of Advocacy and Engagement

Our participation at this year’s ARVO Annual Meeting was a resounding success, serving as a dynamic hub for advocacy, engagement, and collaboration with the vision research community. Throughout the event, our team connected with hundreds of researchers, clinicians, and industry partners, raising awareness about our critical work in advocating for increased funding and support for the National Eye Institute (NEI) and vision research overall. Our booth served as a focal point for discussions on funding opportunities, policy updates, and ways to amplify the voice of the vision research community.



AEVR Leads Two Critical Briefings: Tackling Rare Eye Diseases and Confronting the Growing Challenge of Dry Eye Disease



Pictured L to R: Adriann Keve, Stargardt Patient Advocate; Leonide Saad, Ph.D., Founder and CEO, Alkeus Pharmaceuticals; Abigail Fahim MD, PhD, Assistant Professor, Ophthalmology and Visual Sciences, W.K. Kellogg Eye Center University of Michigan; Eric Fulton, RP Patient Advocate; Dan Ignaszewski, NAEVR/AEVR Executive Director

Congressional Briefing Focuses on Rare Eye Diseases

In a remarkable show of unity and commitment to eye health, the AEVR hosted a highly successful congressional briefing focused on two impactful but lesser-known eye diseases: retinitis pigmentosa (RP) and Stargardt disease. Held at the Capitol, the event brought together policymakers, researchers, patient advocates, and members of the vision health community to shed light on these conditions and underscore the critical importance of research funding.

Despite their relative obscurity, RP and Stargardt disease can significantly affect vision and quality of life if left untreated. RP, a group of genetic disorders, leads to the progressive loss of vision due to the degeneration of the retina, while Stargardt disease, the most common form of inherited juvenile macular degeneration, causes central vision loss, often beginning in childhood or adolescence. Both diseases currently have no cure, making research funding crucial for developing effective treatments.

Abigail Fahim MD, PhD, is a clinician-scientist, provided an overview of the latest scientific advancements in the study of RP. She discussed promising gene therapies and innovative treatment approaches that are currently under investigation, emphasizing the potential for these developments to halt or even reverse

the progression of RP and Stargardt disease. Dr. Fahim underscored the need for sustained and robust funding to continue this vital work.

A highlight of the briefing was the impactful presentation by Leonide Saad, Ph.D., Founder and CEO of Alkeus Pharmaceuticals. Dr. Saad detailed how FDA and NIH/NEI funding has been instrumental in building his company, advancing scientific and clinical research, and developing potential treatments for serious blinding conditions. Since its inception in 2010, Alkeus Pharmaceuticals has been on a mission to transform lives by developing the first potential treatment for Stargardt disease. Through approximately \$4.5M in federal grant funding, Alkeus has interacted with over 4,000 Stargardt patients and enrolled around 400 patients in clinical trials across 20 states. Remarkably, the youngest child treated was just 8 years old, and the longest treatment duration was 7 years.

The briefing also featured heartfelt testimonies from patient advocates who bravely shared their personal experiences living with these rare eye diseases. Their stories highlighted the daily challenges they face and the profound impact that advancements in medical research could have on their lives. One such advocate, Adriann Keve, recounted her journey

with Stargardt disease, describing the gradual loss of her central vision and the difficulties it imposed on her education and career aspirations. "Research is our beacon of hope," she emphasized. "With continued funding, we can look forward to a future where treatments and cures are not just dreams but realities."

Similarly, Eric Fulton, diagnosed with RP at a young age, spoke about the emotional and physical toll of the disease, which his late mother, brother, and now son have. He passionately advocated for increased investment in research, sharing how emerging therapies had given him renewed hope. "Every dollar invested in research brings us closer to breakthroughs that can change lives," he offered.

The briefing concluded with a call to action from NAEVR/AEVR Executive Director, Dan Ignaszewski. He urged policymakers to recognize the profound impact of vision research and to support increased funding for the National Institutes of Health (NIH). "Investing in eye research is investing in the future of millions of Americans affected by these debilitating diseases," says Mr. Ignaszewski. "With your support, we can turn the tide against blindness and improve the quality of life for countless individuals."



Pictured L to R: Molly Chidsey, Dry Eye Disease Patient Advocate; Dr. Alan Kabat, Optometrist and Dry Eye Disease Expert; Rebecca Petris, Founder of the Dry Eye Foundation

Congressional Briefing Highlights the Urgency of Addressing Dry Eye Disease

Our recent Dry Eye Congressional Briefing drew an impressive number of attendees and featuring outstanding speakers who highlighted the critical importance of research and awareness. Over 50 participants, including policymakers, researchers, and advocates, gathered to discuss the latest advancements and challenges in tackling dry eye disease. Our esteemed speakers delivered impactful presentations, underscoring the need for continued federal support for vision research. Their insights and expertise captivated the audience, fostering a deeper understanding of dry eye disease and the urgent need for enhanced treatments and care.

NAEVR/AEVR's Executive Director, Dan Ignaszewski, emphasized the importance of advocacy and funding for vision research. "The success of this briefing demonstrates the critical need for continued investment in vision science. Dry eye disease is a pervasive condition that affects millions, and it's essential that we support research to develop better treatments and improve patients' quality of life," said Ignaszewski. knowledge needed to effectively advocate for vision research funding and its impact on communities.

Dry eye disease affects an estimated 16 million Americans, causing significant discomfort and impairing daily activities. It is a multifactorial condition that can lead to chronic pain, visual disturbances, and decreased quality of life. The prevalence of dry eye disease increases with age, making it a growing concern as the population continues to age.



"Dry eye disease is more than just a minor inconvenience; it's a serious condition that can profoundly affect every aspect of a person's life. We need to raise awareness and advocate for the necessary funding to support research and find effective treatments."

Rebecca Petris
Founder of the Dry Eye Foundation



"Living with dry eye disease has been incredibly challenging. It's crucial that we continue to support research that can lead to better treatments and provide hope for patients like me."

Molly Chidsey
Dry Eye Disease Patient Advocate

Recap of the NAEVR Defense Briefing at the 2024 ARVO Annual Meeting

At this year’s ARVO Annual Meeting, an insightful session explored funding opportunities within the Department of Defense (DoD) through the Congressionally Directed Medical Research Programs (CDMRP). Attendees gained valuable knowledge on the various funding avenues available, including those under the Vision Research Program (VRP), and heard firsthand experiences from researchers who have received CDMRP funding.

The session highlighted that CDMRP funding, appropriated through the DoD budget, amounted to \$1.51 billion in the final FY24 federal budget, with \$20 million allocated to the VRP. The Vision Research Collaborative, a partnership between the VRP and the National Eye Institute (NEI), was also featured for its role in advancing vision research by funding additional meritorious applications.

Success stories from vision researchers who secured funding from 17 different DoD research programs demonstrated the broad range of opportunities available. Insights were provided into FY24 Vision Research Funding, VRP award mechanisms, eligibility, and the review process, with special contributions from Tian Wang, Ph.D., Program Manager of VRP. As vision research advances, CDMRP funding continues to be a crucial resource for impactful research worldwide.



Pictured: Tian Wang, PhD, DoD VRP Manager

VRP Strategic Plan

The CDMRP represents a unique partnership among the U.S. Congress, the military, and the public to fund innovative and impactful medical research in targeted program areas. Programs managed by the CDMRP have formalized strategic plans that identify program specific research priorities; how to best address these urgencies; short- and long-term goals; investment strategies; and ways to identify and evaluate program successes with respect to the priorities.

PROTECT THE NATIONAL EYE INSTITUTE

JOIN US!

Reject NEI Consolidation Proposal

CONTACT FOR MORE INFO:
ADVOCACY@EYERESearch.ORG

Vision loss and blindness have a profound and far-reaching impact on individuals, their families, caregivers, and society as a whole. Push back on the House proposal to consolidate the National Eye Institute (NEI) into a broader Institute on Neuroscience and Brain Research!

Merging the NEI with other institutions would jeopardize its core mission, disrupting both its intra- and extramural research programs that are essential for developing cures and treatments for vision disorders. Such a merger would also impair researchers’ ability to innovate and discover new therapies. We urge you to submit letters to Congress opposing this move. Scan the QR Code to contact Congress today!



Scan me

Welcome Our Distinguished New Partners

We are delighted to extend a warm welcome to our newest partners! Their expertise and dedication will undoubtedly enrich our collaborative efforts and strengthen our collective impact in the field of vision research.

Join us in welcoming the Dry Eye Foundation, Future Leaders in Sight, Mary Tyler Moore Vision Initiative, National Foundation for Eye Research, and Théa Pharmaceuticals as valued additions to our network. Together, we're set to push the boundaries of research, spark innovation, and promote the importance of vision health. We're excited to kick off this journey and look forward to the great things our partnerships will achieve. Welcome aboard!

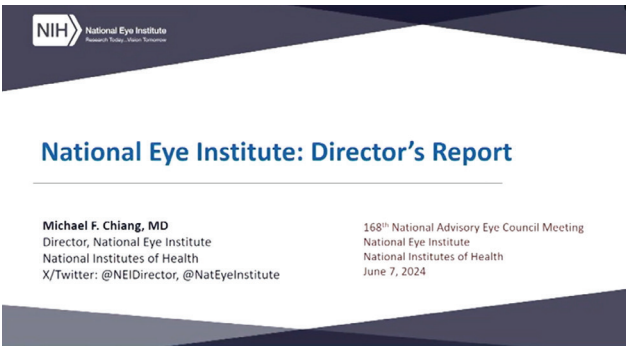
the
dry eye foundation



The 168th National Advisory Eye Council Meeting

In June, the National Advisory Eye Council (NAEC) convened its 168th meeting to discuss critical updates and advancements in vision research. The meeting brought together key stakeholders, researchers, and council members to explore emerging opportunities and challenges in the field of ophthalmology.

Watch the full video by scanning the QR Code.



Shining Light on Vision: Event Highlights



Since our last newsletter, we've participated in several significant events that made a lasting impact. From the Congressional Life Science Fair and reception hosted by The Coalition for the Life Sciences and the Federation of American Societies for Experimental Biology to the American Optometric Association/ American Optometric Student Association Meeting, and the Amgen Advocacy Stakeholder Summit, we've made countless, meaningful connections that will help to advance our mission through advocacy and public education for vision research.

AEVR Featured in *Healio*: Proposed NIH Reforms Threaten Vision Research

We are proud to announce that Executive Director, Dan Ignaszewski, was recently featured in *Healio*, a leading source for healthcare news. In this interview, Dan discusses the serious implications of proposed reforms to the NIH that could merge the NEI into a larger Neuroscience and Brain Institute.



“The more people that can take action, the more opportunity we have to express our concerns with the consolidation effort.”

Dan Ignaszewski



In his interview he underscores the importance of maintaining the NEI as an independent institute to ensure continued progress in vision research. He also calls for the vision community to stay informed and engaged as we advocate to keep vision science a priority within the NIH’s structure.

To learn more about what’s at stake and how you can take action, read the full interview on *Healio* by scanning the QR Code.



10th Annual AEVR Emerging Vision Scientist Program Selects Largest Cohort Yet

The Alliance for Eye and Vision Research (AEVR) is thrilled to announce the selection of candidates for the 10th Annual Emerging Vision Scientist Program. This year’s program is the largest of its kind to date, with 34 outstanding participants from a wide array of specialties within the field of vision research.

The Emerging Vision Scientist Program aims to nurture and support the next generation of vision researchers, providing them with opportunities to engage with policymakers, share their research, and advocate for sustained federal investment in vision science. This initiative is critical for fostering innovative research and ensuring continued progress in the prevention, treatment, and cure of eye diseases.

The Emerging Vision Scientist Program is supported by a generous grant from **Research to Prevent Blindness**, whose organization is dedicated to nurturing and empowering the next generation of vision researchers. Their unwavering commitment to funding innovative research and their mission to prevent blindness and preserve vision is instrumental in driving advancements in vision science.

United Front: 90+ Organizations Rally to Protect Vision Research and Preserve NEI’s Independence

Over 90 organizations representing patients, providers, researchers, and industry have come together to oppose a House proposal that could fundamentally alter the future of vision research. The proposal aims to consolidate the National Eye Institute (NEI) into a broader neuroscience institute, potentially diluting the specialized focus and funding necessary for groundbreaking advancements in eye health.

The vision community is urging Congress to reject this proposal and preserve the NEI as an independent entity within the The National Institutes of Health. The impact of this restructuring could be far-reaching, affecting millions of Americans living with vision impairment and threatening future innovations in eye disease treatment.

The Honorable Robert Aderholt
Chair
House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Washington, DC 20515

The Honorable Tammy Baldwin
Chair
Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Washington, DC 20510

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Washington, DC 20515

The Honorable Shelley Moore Capito
Ranking Member
Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Washington, DC 20510

August 2024

Re: Vision Community Concerns with House Proposal Consolidating the National Eye Institute into a Broader Institute on Neuroscience and Brain Research

Dear Chairs Aderholt and Baldwin and Ranking Members DeLauro and Capito:

Over 90 million Americans 40 years of age or older are experiencing vision impairment. Nearly five million children are living with diagnosed vision conditions. The risk of developing eye disease is projected to double in the next twenty-five years. These sobering statistics compel us, the undersigned organizations that represent patients, providers, researchers, industry, and stakeholders to express our profound concern regarding the proposed drastic restructuring of the National Institutes of Health (NIH) and its potential negative impact on vision research.

As outlined in the recent *Reforming the National Institutes of Health: Framework for Discussion* report published by the Energy & Commerce (E&C) Committee (June 14, 2024), and subsequently included in the House Labor Health and Human Services (LHHS) FY25 Appropriations Bill, the consolidation of the National Eye Institute (NEI) into a broader *Institute on Neuroscience and Brain Research* poses a grave threat to the critical focus required to advance vision research and patient outcomes. Such a restructuring risks diluting the specialized attention and funding necessary for advancing our understanding and treatment of eye diseases.

The distinct and dedicated efforts of the NEI are crucial for addressing the unique challenges and needs of vision health. The proposed consolidation threatens to undermine the enormous progress made in vision research resulting in revolutionary breakthroughs in the treatment of macular degeneration and, diabetic retinopathy as well as other blinding diseases. Future innovative research that will lead to vision preservation or restoration for millions of Americans affected by vision impairment is at risk. While we recognize there may be an interest in NIH reforms, we urge Congress to have an open dialogue with stakeholders, hold public hearings, and provide opportunities for stakeholders to respond appropriately to formal recommendations before implementation.

Another crucial consideration is that many eye diseases, such as retinal vascular disorders, uveitis, corneal injuries and degenerations, and conditions affecting the ocular adnexae (like eye muscle issues, eyelid disorders, and dry eye syndromes), do not involve the central nervous system (CNS) or the peripheral nervous system (PNS). This makes them incompatible with being grouped alongside

NAEVR/AEVR

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Founding Partners



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Gratitude to Our Dedicated Partners

We extend our heartfelt gratitude to our esteemed partners whose unwavering support has been instrumental in driving forward our educational, support, and advocacy initiatives. It is through your commitment and collaboration that we have been able to make significant strides in advancing vision research and promoting awareness of its critical importance.

Your ongoing contributions empower us to continue our vital work in fostering innovation, providing support to those in need, and advocating for policies that prioritize vision health. We are immensely grateful for your dedication and partnership. If you are not yet a partner of our alliances, we invite you to join us in our mission. Contact us today at info@eyeresearch.org to learn more about how you can become a valued member of our community and contribute to our shared vision for a brighter future in eye and vision research.

Partners

