

President's Message

In a challenging budget year, maintaining level funding for NEI amidst the current federal budget environment is undoubtedly a success. However, while level funding is a victory when other agencies saw cuts, it still represents an effective cut after accounting for inflation (3.9% in FY23). Although the absence of outright cuts for vision research is worthy of some celebration, we must redouble our efforts to advocate for increased funding even after inflation in the coming years.

Looking ahead to FY25 funding, there is no doubt that an uphill battle lies ahead. Our members and stakeholders in the vision research community must unite to raise awareness about the value of vision research. NAEVR and AEVR are actively working on programming efforts to foster collaboration among researchers, clinicians, patients, and industry stakeholders to support this collective effort. Together, sharing one voice about the value and impact of vision research, we can make a significant impact and ensure that our priorities are heard by policymakers for FY25.

Despite the budget challenges there are exciting developments on the horizon. Our Alliances are actively seeking stakeholder input into a new strategic plan to guide future initiatives. We are committed to improving and expanding our communication and fostering partnerships with our members and stakeholders to strengthen our collective impact.

With an election year upon us, there is no better time to advocate for increased vision research funding. Educating policymakers and sharing the value of vision research is essential during an election period. Please join us in our education

and advocacy efforts by nominating an emerging researcher for the Alliances' Emerging Vision Scientist program. This highly successful program trains researchers how to communicate their science and become effective advocates. By engaging our policymakers, we can shape the future of vision research and make a lasting impact on eye health worldwide.

Thank you for your continued support and dedication to advancing vision research.

Sincerely,

Steven Feldon, MD, MBA

President, Board of Directors
National Alliance for Eye and Vision Research/
Alliance for Eye and Vision Research



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240.221.2905



info@eyerresearch.org



eyerresearch.org

Legislative Update: Congress Passes FY24 Appropriations

	FY21 Final	FY22 Final	FY23 Final	FY24 Final	FY25 NAEVR Request	FY25 President's Budget
NIH	\$42.93B +3%	\$44.96B +4.72%	\$47.46B +5.6%	\$47.08B -0.8%	\$50.3B +6.84% over FY24	\$50.1B +6.4% over FY24
NEI	\$835.71M +1.4%	\$863.9M +3.4%	\$896.55M +3.8%	\$896.55M +0%	\$1B +11.5% over FY24	\$898.82M +0.3% over FY24
DOD VRP	\$20M +0%	\$20M +0%	\$20M +0%	\$20M +0%	\$30M +50%	N/A

- The FY23 budget included funding for ARPA-H within NIH at \$1.5B and was level-funded in FY24
- The Fiscal Responsibility Act of 2023 (Debt Ceiling Agreement) put caps on federal spending for FY24 and FY25

Congress passed, and on March 23, the President signed the final set of appropriations bill for FY24 funding, providing level funding for critical vision research programs, including the National Eye Institute (NEI) and the Department of Defense's (DoD) Vision Research Program (VRP) within the Congressionally Directed Medical Research Program (CDMRP).

Dan Ignaszewski, Executive Director of the National Alliance for Eye and Vision Research (NAEVR) and the Alliance for Eye and Vision Research (AEVR), expressed appreciation for the continued support for vision research but emphasized the challenges posed by level funding. "While we are grateful for the sustained funding commitment from Congress, it's important to recognize that level funding, in the face of rising costs, effectively represents a cut in resources for vital vision research programs."

Of the institutes at NIH, 19 received level funding, five along with the Office of the Director received decreases, and three received small increases.

Institutes that saw decreases:

- Office of the Director (-1.9%)
- NCI (-1.3%)
- NIDDK (-5.4%)
- IGMS (-.5%)
- NIMH (-6.4%)
- NINDS (-7.5%)

Institutes that saw increases:

- NIA (+2.3%)
- NICHD (+.6%)
- NIMHHD (+1.9%)
- NCATS (+.5%)

Overall, the budget decreases NIH funding by 0.8% (a decrease of \$378M). The Alliances have continued to highlight the need for adequate resources to address emerging health challenges and sustain progress in medical research specifically in vision with an emphasis on the projected rising prevalence of vision loss. "We share concerns about the impact this will have on vision researchers," said Ignaszewski. "Vision research plays a critical role in addressing the burden of eye diseases and improving public health outcomes. As such, it's imperative that FY25 funding reflects a commitment to increasing resources for vision research."

Looking ahead to the FY25 appropriations process, the Alliances are emphasizing the need for sustained advocacy efforts to ensure that vision research funding receives the attention and support it deserves. We are leading efforts to urge Congress to prioritize an increase in funding for vision research in FY25 to \$1B for NEI and \$30M for the VRP.

The President's budget for FY25 requests a very modest increase for NEI of 0.3% or \$2,251,000 up to \$898.8M. While we recognize and appreciate the Administration prioritizing an increase, more funding is necessary to accurately reflect the value of vision research and provide sustainable funding to account for inflation plus growth.

Our Alliances remain committed to advocating for increased funding for vision research and will continue working with stakeholders and policymakers to advance this critical priority.

ARVO Advocates Rally for Congressional Action

In a concerted effort to influence the ongoing budget deliberations in Congress, The Association for Research in Vision and Ophthalmology recently mobilized its dedicated advocates for the organization's annual Advocacy Day on January 26. Amidst the finalization of the Fiscal Year 2024 appropriations bills, particularly concerning the vital funding allocated to the NEI, ARVO members took to Capitol Hill to make their voices heard.

Gathering on January 26, the ARVO Annual Meeting Planning Committee (AMPC) spearheaded the Advocacy Day, strategically timed as Congress navigated the intricacies of FY24 budgetary decisions. With the federal government operating under a Continuing Resolution (CR), maintaining funding levels from the previous fiscal year, the urgency of advocating for robust funding for vision research was paramount. ARVO advocates also set a stake in the ground requesting \$1B for NEI in FY25 funding.

Comprising a diverse cohort of domestic and international advocates, including AMPC representatives, Science Communication Training Fellows, and members of ARVO's Advocacy and Outreach Committee, the advocates conducted nearly 80 visits to Congressional offices. These engagements targeted key committee members overseeing NIH funding and provided an opportunity to emphasize the critical importance of NEI funding.

A noteworthy aspect of this year's advocacy efforts was the participation of nine advocates who had previously undergone training through AEVR's Emerging Vision Scientists program. Equipped with the necessary advocacy skills and insights gained from the program, they played a pivotal role in articulating the value of vision research to policymakers.

Dan Ignaszewski, Executive Director, NAEVR/AEVR, provided invaluable guidance to advocates, preparing them for potentially challenging fiscal and political discussions. Armed with detailed talking points, advocates effectively conveyed the significance of their research and underscored the imperative of robust federal funding for the NEI.

As budget negotiations were finalized, ARVO remained steadfast in its commitment to advocating for sustained and increased funding for vision research. By amplifying their collective voice and engaging policymakers, ARVO advocates aim to secure the resources necessary to advance groundbreaking research in ophthalmology and ultimately improve patient outcomes.





Pictured L to R: Dianne Aronian, AMD Patient Advocate; Amir Kashani, MD PhD, Professor of Ophthalmology, Johns Hopkins University's Wilmer Eye Institute; Neena Haider, PhD; Mark Roser, AMD Patient Advocate; Jennifer Williams, Communications & Engagement Director, AMDF; Matthew Levine, Grants, Advocacy and Partnerships Director, AMDF; Dorothee Wool and her husband, AMD Patient Advocates; Ryung-San Lee, Vision Researcher; Dan Ignaszewski, Executive Director, NAEVR/AEVR; Connor McAulay, Vision Researcher

AEVR Hosts Congressional Briefing on AMD, NAEVR Advocacy Day on Capitol Hill

In observance of February as the annual Age-related Macular Degeneration (AMD) and Low Vision Awareness Month, AEVR and the American Macular Degeneration Foundation (AMDF) came together for Access in Sight – AMD Advocacy and Action Week, held the last week of February. This groundbreaking collaboration featured a significant Congressional Briefing and a “Day on the Hill,” where advocates from across the nation convened to meet with Congressional offices.

AMD, a degenerative condition affecting the retina and retinal pigment epithelium, causes central vision loss, leading to substantial challenges in daily life and emotional well-being. As one of the leading causes of vision loss, AMD affects 20 million Americans, a number projected to double by 2050. The briefing centered on the critical need for research investment to advance treatments and cures for AMD as its prevalence continues to rise.

Congressman Pete Sessions (R-TX-17), a vocal supporter of vision research, joined the AMD Congressional Briefing to emphasize the importance of expediting AMD treatments. His advocacy efforts have spurred initiatives like the 2017 3D Retina Organoid Challenge, encouraging the

development of retina-like tissues.

NEI-funded research plays a crucial role in understanding the mechanisms underlying AMD, paving the way for innovative approaches to its prevention and treatment. Clinical trials such as AREDS have provided valuable insights and led to FDA-approved therapies, marking significant progress in AMD treatment.

The briefing, co-hosted by AMDF, Research to Prevent Blindness, ARVO, Apellis and Genentech, underscored the collective commitment to vision research. Former Associate Professor Neena Haider, PhD, highlighted the transition of NEI-funded research into industry-driven therapies. Amir Kashani, MD, PhD of Wilmer Eye Institute provided insights into the prevalence, causes, and impact of AMD for congressional staff and highlighted advancements in AMD research.

Advocates shared compelling stories during the briefing, urging lawmakers to prioritize initiatives benefiting AMD patients. AEVR and AMDF also provided a mixed-reality experience with VisionAid's eye disease simulator, offering insights into AMD-related vision loss.

NAEVR trained AMD patient advocates

to effectively advocate for policy changes, including increased research funding and improved healthcare accessibility. Their unified efforts underscored the importance of advancing vision health initiatives.

Together our organizations are committed to elevating eye health and driving positive change on Capitol Hill. By harnessing our collective efforts, we aim to secure funding for vision research and address the challenges faced by individuals with AMD related vision loss.



“Many factors contribute to the prevalence of AMD, including smoking, high blood pressure, high cholesterol, cardiovascular disease, obesity, light exposure, and poor diet,” offered speaker Amir Kashani, MD PhD, Professor of Ophthalmology at Johns Hopkins University's Wilmer Eye Institute. “Clinical trials (AREDS) have provided a clinical staging system by which we can classify patients even before they have symptoms.” Dr. Kashani highlighted the advancements in treatment of AMD and emphasized progress happening from the NEI-funded research.



Nurturing Future Visionary Leaders: AEVR's Emerging Vision Scientist Program

AEVR is proud to announce its now accepting applications until May 31 for the prestigious Emerging Vision Scientist program. This initiative, part of AEVR's Research Saving Sight, Restoring Vision Initiative, is supported by Research to Prevent Blindness and cultivates the next generation of vision research leaders.

The program offers early-stage investigators a unique opportunity to gain insight into the legislative process and acquire essential skills to effectively communicate their research to policymakers. Through a series of tailored events, participants will have the chance to advocate for the value of vision research while connecting with key stakeholders in the field.

Key components of the program include:

AEVR Congressional Briefing: Attend an exclusive briefing to observe how vision research is presented to policymakers, gaining valuable insights into advocacy.

Communication Training: Learn how to effectively articulate the significance of their research to members of Congress and other key stakeholders, enhancing their communication skills.

Poster Presentation: Showcase their research through audience-friendly posters at an AEVR-hosted Congressional Reception, providing a platform to engage with policymakers and vision research leaders.

Advocacy Training: NAEVR will provide advocacy training to equip participants with the tools and knowledge needed to effectively advocate for vision research funding and its impact on communities.

The Emerging Vision Scientist Program represents a pivotal opportunity for early-stage investigators to make a meaningful impact in the field of vision research while honing their advocacy and communication skills. Join us in nurturing the visionary leaders of tomorrow and advancing the frontiers of vision science. **Apply now to be part of this transformative experience!**



"After participating in the Emerging Vision Scientist program, I feel empowered to advocate for the importance of vision research with policymakers. The opportunity to present my research at the Congressional Reception and engage with members of Congress was truly invaluable. This program has equipped me with the skills and confidence to make a meaningful impact in advancing vision science."

Safal Khanal, OD, PhD
Assistant Professor
The University of Alabama at Birmingham

AEVR and CDMRP VRP: Uniting for Vision Research Solutions

Bridging Research Gaps: The Vision Research Program's Impact on Military Eye Health

Established as part of the Fiscal Year 2009 Appropriations, the Department of Defense's (DoD) Vision Research Program (VRP) stands as a cornerstone of funding dedicated to advancing research aimed at preventing, diagnosing, and treating vision loss and dysfunction stemming from combat-related trauma. Under the management of the Congressionally Directed Medical Research Program, the VRP has been instrumental in allocating over \$200M to support groundbreaking research initiatives with Congress including level funding of \$20M for FY24 this Spring.

Since its inception, the VRP, which is one of the 38 medical research program's managed by the DoD, has been at the forefront of addressing critical areas such as penetrating eye injuries, corneal healing, retinal and corneal protection, traumatic brain injury -related visual dysfunction, eye blast phenomena, and vision rehabilitation. These efforts have been pivotal in bridging research gaps identified by the DoD, ensuring that advancements in vision science translate into tangible benefits for military personnel and veterans affected by combat-related ocular injuries.



Q. Tian Wang, PhD, DoD VRP Manager

See You at ARVO!

NAEVR Defense Briefing Monday, May 6 7:00 - 8:30AM PT Room 2AB

Join us at this year's ARVO Annual Meeting on May 6 at 7AM PT for an insightful session on the CDMRP. Discover the diverse funding opportunities provided by the DoD for both domestic and international researchers.

During this session, esteemed researchers who have previously received funding from the VRP will participate in a panel discussion, sharing their valuable insights and experiences with the program.

Last year's ARVO Annual Meeting witnessed an impressive turnout, with over 100 researchers actively engaging in the session. Don't miss this opportunity to learn more about the CDMRP and gain valuable knowledge from experienced VRP-funded researchers.



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.



Adapting for Tomorrow: The DoD VRP Readies for Future Challenges



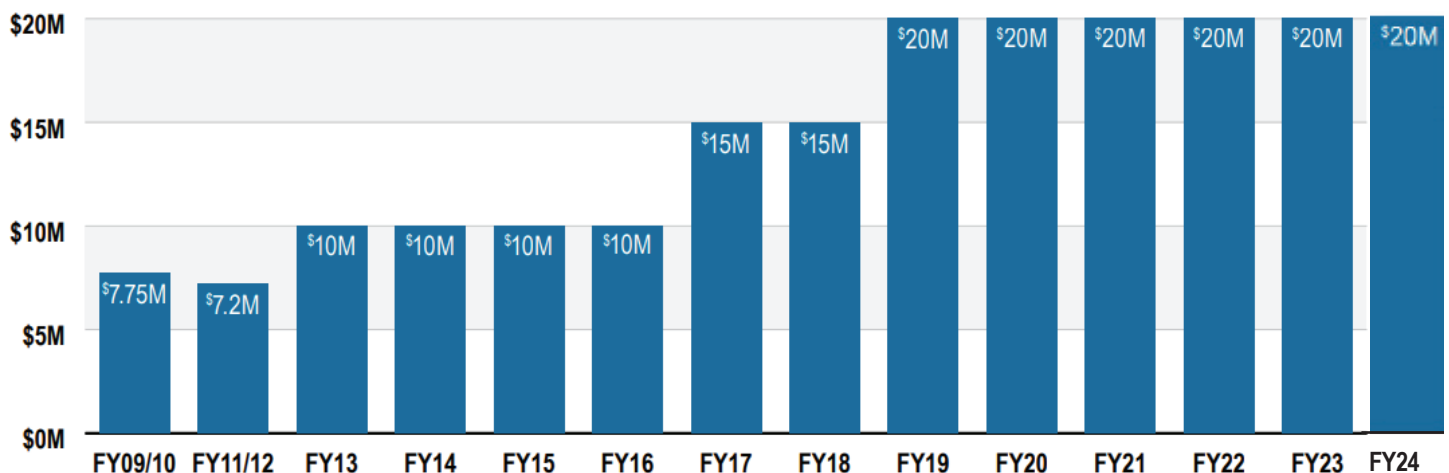
The DoD VRP continues to spearhead innovative research initiatives aimed at enhancing the visual health and performance of military personnel and civilians alike. With a commitment to supporting cutting-edge visual trauma research, the VRP recently convened its programmatic review committee in March to evaluate proposals for FY23 awards.

The committee is tasked with ensuring that proposed research projects align with the VRP goals and priorities. The VRP has a two-stage review process, a scientific review followed by programmatic review. Committee members are experts in vision science, military medicine, and related disciplines, whose collective expertise lends insight into the selection process of grant proposals as they relate to the intent of the program. NAEVR's Executive Director Dan Ignaszewski sits on the committee.

During the review, the committee scrutinizes each proposal, recognizing the scientific merit score, and considers its relevance to the portfolio, innovation, and potential impact on advancing the treatment of ocular trauma. The committee identifies projects that can address critical gaps in military vision research and improve clinical outcomes for individuals with visual impairment.

The committee also discussed needs for the VRP in FY24 by engaging in strategic discussions to identify emerging research priorities and strategic focus areas. By proactively identifying and setting priorities, the VRP aims to strategically allocate resources toward research endeavors that hold the greatest potential for transformative impact in line with the directive of the program.

VRP Appropriation, FY 09-FY24



Introducing Our Esteemed 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 Alkeus Pharmacueticals and Oyster Point Pharma as valued additions to our network. Together, we are poised to advance groundbreaking research, drive innovation, and advocate for the importance of vision health.

We are thrilled to embark on this journey together and look forward to the meaningful contributions our partnership will bring. Welcome aboard!



Alkeus was co-founded by Leonide Saad, Ph.D. and Ilyas Washington, Ph.D. with the goal of treating degenerative eye diseases in a completely new way: developing a molecule that could reduce the potential for toxicity when vitamin A dimerizes — clumps —in the eye. This dimerization is a key underlying contributor to the irreversible retinal damage that is common to a number of eye diseases. Alkeus has steadily progressed its lead molecule gildeuretinol (ALK-001), demonstrating its tremendous promise and advancing a comprehensive clinical program.

Alkeus recently sponsored The Carroll Center's Stargardt's Summit. The event provided an opportunity for the Stargardt community to learn about the newest research, explore adaptive living resources, and hear impactful patient stories. Alkeus is proudly supporting AEVR's Rare Eye Disease Congressional Briefing in May.



Oyster Point is a biopharmaceutical company focused on the discovery, development, and commercialization of the first-in-class therapies to treat opthalmic disease. The company strives to advance breakthrough science and deliver therapies skeeing to address the unment needs of patients and eye care professionals.

Oyster Point colleagues working tirelessly to connect with eye care professionals across the country and on behalf of patients with dry eye disease. They seek to deliver innovative and transformational therapies to positively impact the quality of patients' lives.

Oyster Point is proudly supporting AEVR's Rare Eye Disease Congressional Briefing in May.



Shining Light on Vision: Event Highlights



Since our last newsletter, we've been immersed in a myriad of impactful vision-related events. From the Annual Vision Research Funding Partnership Meeting to the ASCRS Annual Meeting and the NIH Optical Coherence Tomography Symposium our participation has been marked by collaboration, knowledge sharing, and advocacy.

As we look ahead, we're eager to continue our in-person endeavors alongside our esteemed partners. We anticipate further enriching engagements and meaningful collaborations that will advance our shared mission in the field of vision research.

AEVR's Rare Eye Disease Congressional Briefing: Illuminating Retinitis Pigmentosa and Stargardt Disease

AEVR is thrilled to unveil its upcoming Congressional Briefing, dedicated to shedding light on two lesser-known yet impactful eye diseases: retinitis pigmentosa (RP) and Stargardt disease. Despite their lower profile, these conditions can have profound effects on vision and quality of life if left untreated.

Set to take place on May 14 at 9:00AM in Rayburn House Office Building 2075, this briefing will feature esteemed guest speakers who are leading the charge in research and innovation within the field. One such speaker is Dr. Leonide Saad, Ph.D., Co-Founder, President, and Chief Executive Officer of Alkeus Pharmaceuticals—an AEVR Member Foundation. Dr. Saad's groundbreaking work in developing ALK-001 for Stargardt disease has positioned him as a pioneer in the field, with significant contributions to clinical research and treatment development.

Joining Dr. Saad will be Abigail T. Fahim, MD, PhD, Assistant Professor of Ophthalmology and Visual Sciences at University of Michigan Medicine's Kellogg Eye Center. Dr. Fahim's expertise lies in investigating retinal pigment epithelial cell dysfunction in inherited retinal diseases, with a focus on understanding disease mechanisms and identifying therapeutic targets. Her research has the potential to revolutionize our understanding of retinal diseases and pave

the way for novel treatment approaches.

The briefing will also provide a platform for patients affected by these blinding eye diseases to share their experiences. Their firsthand accounts will offer valuable insights into the challenges faced by individuals living with RP and Stargardt disease, highlighting the urgent need for continued research and support.

Don't miss this opportunity to learn more about these lesser-known eye diseases and the groundbreaking research being conducted to combat them. Join us for an enlightening discussion and a glimpse into the future of vision research and treatment.



*Dr. Leonide Saad, Ph.D.
Co-Founder, President, and CEO
Alkeus Pharmaceuticals*



*Abigail T. Fahim, MD, PhD,
Assistant Professor of Ophthalmology
and Visual Sciences University of
Michigan Medicine's Kellogg Eye Center*

NAEVR Shares Visionary Insights at Research to Prevent Blindness Board of Trustees Meeting

At the recent Research to Prevent Blindness Board of Trustees meeting, the Alliances presented the program and strategic planning initiatives to raise awareness about vision research funding. NAEVR emphasized how educational support for vision research is not just about the research, but also supporting efforts to bring outcomes to the care continuum for patients and providers. Funding science leads toward new treatments and therapies and helps patient accessibility.



Research to Prevent Blindness

The Alliances also emphasized the focus on developing support for grassroots and grassroots programs. By engaging members and stakeholders in support of vision research, the Alliances are able to bring together researchers, providers, patients, and industry to advocate for vision research funding that benefits all stakeholders. The Alliances also shared the development of the new materials and programs that support the connection of all stakeholders in an effort to successfully advocate for vision research funding within their communities.

Unlocking the Potential of Optical Coherence Tomography: A Transformative Journey in Eye Care

Members of NAEVR/AEVR recently had the privilege of attending the National Eye Institute (NEI)'s symposium titled "Optical Coherence Tomography: Celebrating its Transformative Impact on Eye Care and Beyond" at The National Institutes of Health. This symposium marked a significant milestone in the evolution of eye care, as it delved into the revolutionary advancements brought about by Optical Coherence Tomography (OCT).

Over the course of two days, participants were immersed in lectures and discussions that showcased the diverse range of applications of OCT in both research and clinical settings. From its humble beginnings to its status as a cornerstone of ophthalmic practice, OCT has indeed revolutionized how eye conditions are diagnosed and managed.

At the heart of OCT's transformative impact lies its ability to provide high-resolution, cross-sectional images of the eye in real-time, without the need for invasive procedures. This non-invasive nature has not only enhanced patient comfort but has also paved the way for earlier detection and more accurate monitoring of conditions such as glaucoma, macular degeneration, and diabetic retinopathy.

Moreover, OCT's versatility extends beyond the realm of ophthalmology, finding applications in fields like dermatology and cardiology. Its precision imaging capabilities have enabled researchers and clinicians to gain deeper insights into various diseases and conditions, leading to more targeted treatments and improved patient outcomes.

As we reflect on the insights shared during the symposium, it becomes clear that OCT has transcended its role as a diagnostic tool to become a catalyst for innovation and collaboration across disciplines. By harnessing the power of OCT, we are not only transforming the landscape of eye care but also making strides towards a future where everyone can enjoy the gift of healthy vision.



NAEVR/AEVR

5515 Security Lane, Suite 500
Rockville, Maryland 20852-1606

Founding Members



Association of University
Professors of Ophthalmology

Gratitude to Our Dedicated Members

We extend our heartfelt gratitude to our esteemed members 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 member of our alliances, we invite you to join us in our mission. Contact us today at info@eyerresearch.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.

Members

