

# **CONTRIBUTOR REPORT**

National Alliance For Eye And Vision Research | Alliance For Eye and Vision Research

## PRESIDENT'S MESSAGE

**New Beginnings and Opportunities** 



Spring represents new growth and new opportunities. This spring, the Alliances are beginning 2022 with new leadership, with Dan Ignaszewski as our new Executive Director, and with an eye to building on the foundation of the Alliances' past success. 2022 has already seen the Alliance for Eye and Vision Research (AEVR) delivering on an aggressive schedule of congressional briefings, and the National Alliance for Eye and Vision Research (NAEVR) supporting increased funding for research by empowering advocates and engaging with Congress.

You'll see throughout this report that 2022 has already been a busy year with educational programming, publication of a new *JAMA Ophthalmology* article, and the passage of the Federal budget for the fiscal year 2022 (FY22), and we expect it will only get busier. *The Legislative Update* section of this report provides details around the passage of the Federal FY22 budget in March. The budget included \$863.9 million in funding for the National Eye Institute (NEI) within the National Institutes of Health's (NIH), and \$20

million in funding for the Vision Research Program (VRP) within the Department of Defense's (DoD) Congressionally Directed Medical Research Program (CDMRP). NAEVR worked with advocates to support the passage of the FY22 budget, and since its passage, has quickly pivoted to the fiscal year 2023 (FY23) funding requests.

In the *Education Update* of this report, you'll find details about AEVR's 2022 Congressional Briefing plans under its *Research Saving Sight, Restoring Vision Initiative*. This initiative includes five Congressional briefings in 2022, including AEVR's recently hosted glaucoma briefing conducted during World Glaucoma Week in March. We're also excited for AEVR to host its 8th annual *Emerging Vision Scientists (EVS) Day* in September and encourage all the Departments of Ophthalmology and Schools and Colleges of Optometry to nominate early-stage investigators to participate where they will be able to share their cutting-edge research and advocate with their Congressional delegation. We are also exploring new ways of engaging past EVS participants in continued advocacy efforts on behalf of the vision research community.

The Alliances have also welcomed two new Board members since our last *Contributor Report*, electing Joan O'Brien, MD who is immediate past Chair of the Department of Ophthalmology at the University of Pennsylvania Health System, as well as Eduardo Alfonso, MD who serves as Chairman of the Department of Ophthalmology of the University of Miami Miller School of Medicine, and Director of the Bascom Palmer Eye Institute. With these elections, the Boards of the Alliances remain committed to working with our members and organizational leadership to maximize the Alliances' impact and expand opportunities for member engagement.

On behalf of the NAEVR and AEVR Boards, we also want to thank our outgoing Directors, Dr. Peter McDonnell, and Dr. Stephen McLeod for their contributions and service to our community. Finally, we want to thank all of you for your continued support of the Alliances and to ask for your ideas and suggestions. Our membership councils have provided important feedback and thoughtful discussions of potential new growth for the Alliances' activities. We look forward to working with you in 2022 and for many years to come.

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#### NAEVR Events: NAEVR at the 2022 ARVO Annual Meeting

Sunday, May 1 - Wednesday, May 4 NAEVR Central, 8:30 am - 5:00 pm Daily, Colorado Convention Center

Monday, May 2
NAEVR's Defense-Related Vision Research Opportunities
Session
7:00 am - 8:00 am, Mile High Ballroom 1AB, Colorado
Convention Center

### NAEVR SCORECARD LEGISLATIVE ISSUES

	FY2019	FY2020	FY2021	FY2022
	FINAL	FINAL	FINAL <sup>^</sup>	FINAL
NIH	\$39.08 B	\$41.68 B	\$42.93 B	\$44.96 B
	+5.4%	+6.7%	+3%	+4.72%
NEI	APPROP: \$796.5 M +3.1% OPERATIONAL NET \$793.8M	APPROP: \$824.09 M +3.5% OPERATIONAL NET \$823.3M	APPROP: \$835.71 M +1.4% OPERATIONAL NET \$833.012M	\$863.9 M +3.4%

- NEI Operational Net reflects \$7.9 M transferred back to NIH Central of Soca funding
- Does not include research relief funding for NIH grantees.

### **FY23 APPROPRIATIONS**

The FY23 budget process has already begun. The Administration released the FY23 budget request on March 28, including \$853.4 million for NEI. Due to late passage of the FY22 budget, agencies based level. The administration intended to include an increase for NEI. however, the amount is less than the FY22 enacted level due to their starting point. Congress will work off the final FY22 enacted level for FY23. With the President's request being less than anticipated, and with 2022 being an election year, there are unique challenges and opportunities ahead.

Appropriations Committee Chair Patrick Leahy, Ranking Member Richard Shelby, and Labor, Health and Human Services Subcommittee Ranking Member Roy Blunt have announced their retirements vision. this year after supporting seven consecutive years of growth for NIH. NAEVR NAEVR looks forward to working with them, and Subcommittee Chair Patty Murray in the Senate, along with Appropriations Chair Rosa DeLauro (D-CT), and LHHS Subcommittee Ranking Member Tom Cole (R-OK) in the House to continue to support increases for NIH, and NEI specifically. NAEVR

has already met with appropriators for the Labor, Health, and Human Services subcommittee and the Defense subcommittee to discuss increases for vision research.

requests on the FY21 enacted NAEVR is requesting an increase from \$863.9 million included in the FY22 budget to \$950 million in the FY23 budget to account for inflation plus growth and to recognize and build on the success of vision researchers. While this is a substantial request, we also recognize that without this needed investment in vision research, the expected doubling of Americans living with eye and vision conditions by 2050 will continue unabated. Research provides the tools to improve diagnosis, interventions, therapies, and ultimately patient outcomes and may help us reach NEI's audacious goal to restore

> also developed has coordinated talking points for our members and strategic partners to support increasing investments at NEI and the DOD. Congress anticipates moving through the budget process in normal order and we expect to be able to share more in our Summer Contributor Report.

## **FY2022 APPROPRIATIONS**

On March 11, President Biden signed the Consolidated Appropriations Act. 2022. \$1.5 trillion **Omnibus** Fiscal Year 2022 (FY22) Appropriations bill, which combines all the FY22 spending bills into one package. The signing comes after Congress finalized the bill earlier in the week, with the House passing the package on March 9 and the Senate following suit on March 10 with bipartisan support.

The omnibus delivers on priorities for both parties and includes a compromise between earlier House and Senate bills for NIH and NEI funding. The omnibus includes \$44.959 billion for the National Institutes of Health (NIH), an increase of \$2.025 billion or 4.72 percent over FY21. For the National Eve Institute (NEI), the bill provides \$863.918 million, an increase of \$28.204 million or 3.26 percent over FY21.

President Biden's action before just the came expiration of a Continuing Resolution (CR), set to expire at midnight on March 11, the third CR that Congress had been forced to pass due to the delay in finalizing the FY22 spending bills before the start of the fiscal year on October 1 of last year.

# EDUCATION AEVR Celebrates World Glaucoma Week with Congressional Briefing







Thomas Brunner, President & CEO, Glaucoma Research Foundation



Trinh Green, MD, Glaucoma Research Foundation Patient Representative



On March 8, the Alliance for Eye and Vision Research (AEVR) celebrated *World Glaucoma Week* by conducting its first virtual *Research Saving Sight, Restoring Vision* Congressional Briefing of 2022, *Understanding Glaucoma Patients: Health Disparities and Unmet Needs.* AEVR's *Research Saving Sight, Restoring Vision Initiative* is a sustained activity to educate about the value of eye and vision research and the enormous strides that National Eye Institute (NEI) funded research has made to establish improvements to diagnosis, treatments, therapies, and outcomes for eye and vision care.

The Briefing featured experts in glaucoma, including Dr. Leon Herndon, professor of ophthalmology at Duke University Medical Center, Tom Brunner, President & CEO of the Glaucoma Research Foundation, and Dr. Trinh Green, a practicing physician who was diagnosed with glaucoma at the age of 21.

After outlining an introduction to glaucoma, Dr. Herndon shared that the prevalence of glaucoma is six to eight times higher in African American patients who are also at fifteen times higher risk of blindness. He also shared that glaucoma has several consequences on a patient's vision, including not only the loss of visual field creating blind spots, but also a loss of contrast sensitivity, loss of visual acuity, and problems with glare and light sensitivity.

Once a patient is diagnosed with glaucoma, Dr. Herndon emphasized that medication adherence is vital in stemming the tide of the disease. Treatments for glaucoma include traditional eye drops, and over the past several years, advancements and other treatments have been identified and include injectable sustained-release implants, laser treatment, surgical procedures, long-tube shunts, and micro-invasive glaucoma surgery. As part of his work in West Africa, Dr. Herndon's research on the genetic links related to glaucoma may lay the foundation for novel therapeutic interventions and increase awareness of glaucoma. Health disparities that exist for patients, disparities in the ophthalmology profession, and disparities in accessing critical glaucoma care were all identified as issues that need to be addressed and improved.

Tom Brunner introduced participants to the Glaucoma Research Foundation whose mission is to cure glaucoma and restore vision through innovative research. Mr. Brunner provided a global perspective of glaucoma emphasizing that this disease has no cure. With an estimated 60 million cases worldwide, and an estimated 111 million people globally expected to have glaucoma by 2040, the global figures mirror those projections in the United States. With this understanding, and to address the looming epidemic, Mr. Brunner emphasized the need to continue to invest in

promising research to improve outcomes for glaucoma patients.

From a patient perspective, Dr. Trinh Green shared her personal experience with Glaucoma. When she was diagnosed at 21, she was being monitored for a different eye condition. At that time, her ophthalmologist noticed the markers of glaucoma. For the first seven years after her diagnosis, Dr. Green focused on taking eye drops and didn't experience substantial loss in vision. At 28, Dr. Green shared that she began losing vision in her left eye and was advised to have a trabeculectomy to create a new pathway for fluid to be drained to save her eyesight. In subsequent years, despite adherence and continued engagement with specialists, Dr. Green continued to lose peripheral vision.

Treatments for Dr. Green have included revisions to her trabeculectomy, express shunts and Ahmed valves inserted into her eyes, a laser diode cyclophotocoagulation procedure, and a corneal graft to address side effects. Advancements in research have helped to improve these interventions and they have continued to allow Dr. Green to see. While Dr. Green shared that she has lost about 50% of the vision in her left eye and some vision in her right, she's been fortunate that her central vision is still very good. While glaucoma affected Dr. Green's dreams, her day-to-day life, and her career path, the research that has been done on glaucoma to date has helped provide new and innovative interventions and therapies, and she emphasized the continued need for research for herself, and for future generations.

Each of the panelists emphasized the value that research has played to date and the new opportunities on the horizon. The National Eye Institute (NEI) is funding research projects including artificial intelligence to improve diagnosis, improved clinical methods, and for new and improved interventions, devices, and therapies that preserve sight and could restore vision.

AEVR was pleased to be able to host this Congressional Briefing during *World Glaucoma Week*, which is being celebrated March 6-12, 2022 with events around the world. The Briefing continued to highlight the value for eye and vision research in the care of glaucoma patients and AEVR thanks its supporters who helped make this event possible, including:

- Research to Prevent Blindness
- American Glaucoma Society
- ARVO (which provided steaming support)
- Glaucoma Research Foundation
- Optometric Glaucoma Society
- Glaukos

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### **DEFENSE-RELATED VISION FUNDING**

Since it was created by congress in FY09, the Vision Research Program (VRP) within the Congressionally Directed medical Research Programs (CDMRP) has been funded by Congress at \$144.95 million through FY21. Through FY20, VRP has made 135 awards for a total of \$133 million with FY21 awards pending.

# NAEVR Participates in VRP Meetings and Joins Programmatic Review Panel

On January 31, NAEVR Director of Government Relations David Epstein participated in the VRP's *Retinal and Optic Nerve Injury Research and State of the Science* Meeting, which was held virtually due to the pandemic. Researchers who have received funding from the VRP around retinal and optic nerve injury presented updates on the status of their investigations.

On March 14, Mr. Epstein attended VRP's Programmatic Review session, at which the Programmatic Panel members reviewed proposals for the FY21 funding cycle, paired their scores with the scores from the Peer Reviewers, and determined funded projects. On March 17, he attended the VRP's FY22 Vision Setting Meeting, at which the Program panel selected which grant mechanisms and research focus areas will be used for the FY22 funding cycle.

In addition to David's participation, on March 17, at VRP's request, Alliances' Executive Director, Dan Ignaszewski was asked to join the Programmatic Review Panel as an active member and presented about federal investment in vision research. At the inception of the VRP program, the Alliances staff were part of the programmatic review, but since 2014, due to previous executive orders, Alliances staff were unable to remain panelists. With updated executive orders, moving forward, Dan will be able to work with other members of the VRP program to review submissions and identify updates to the vision and grant mechanisms for VRP. Dan brings experience to the VRP program having served in his previous role on the CDMRP Orthotic and Prosthetic Outcomes Review Panel (OPORP) for over three years.

# CDMRP Vision Manager Dr. Tian Wang to Speak at the ARVO Annual Meeting

NAEVR will provide its May 2 Defense Vision Research Opportunities session at the ARVO Annual Meeting, as it did annually before the pandemic. VRP Program Director Quntian Wang, PhD has agreed to speak at the session. While attending the Annual Meeting, Dr. Wang will also meet with researchers interested in defense research funding opportunities, holding both in-person and virtual meetings with researchers unable to attend the Annual Meeting.

### FY22: Congress Funds VRP at \$20 Million

On March 11, President Biden signed the FY22 Omnibus appropriations bill which included VRP funding at \$20 million for the fourth year. NAEVR and its advocacy partners, including Blinded Veterans Association, ARVO, the American Academy of Ophthalmology, and the American Optometric Association, had requested \$30 million. NAEVR justified this increase by citing the results from AEVR's 2018 update of the Cost of Military Eye Injury study, published in the May/June 2019 edition of the journal Military Medicine, that estimated total cost from the 2000-2017 timeframe at \$41.5 billion, with \$40.2 billion of that cost reflecting the present value of a lifetime of long-term benefits, lost wages, and family care. There was also a specific provision within the Omnibus bill that clarifies intent and permits agencies to use appropriated funds for "interagency funding for coordination with, participation in, or recommendations involving activities of the U.S. Army Medical Research and Development Command, the Congressionally Directed Medical Research Programs, and the National Institutes of Health research programs." NAEVR sees this as an opportunity for enhanced collaboration across agencies to support strong research proposals.

#### FY23: NAEVR to Request \$30 Million for VRP

NAEVR has already begun for advocacy efforts for FY23. NAEVR is requesting VRP funding at a level of \$30 million, after 4 years at a level of \$20 million, and will coordinate with its advocacy partners. NAEVR continues to submit Programmatic Requests to Congressional offices and we are meeting with staff to support the funding request.



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