NAEVR AEVR

WINTER/SPRING 2021

CONTRIBUTOR REPORT

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

PRESIDENT'S MESSAGE

Messaging About the Value of Vision Research with a New Administration and Congress

The Boards hope that you are staying healthy as we begin to see light at the end of the tunnel with expanding COVID-19 vaccinations. Despite the pandemic's challenges, the NAEVR and AEVR Alliances have proceeded unabated with their respective virtual advocacy and educational activities on behalf of the eye and vision research community, as detailed in this Report.

Per the *Scorecard* Legislative Issues section, with Congress finalizing and the President signing final Fiscal Year (FY) 2021 appropriations in late December 2020, the new 117th Congressional leadership has focused on passing President Biden's $1.9 trillion *American Rescue Plan Act of 2021*, which he signed into law on March 11. Concurrently, NAEVR began its advocacy for FY2022 National Institutes of Health (NIH) and National Eye Institute (NEI) funding increases, as well as an increase for the Peer-Reviewed Vision Research Program within the Department of Defense (see Report's back page).

Your support throughout the pandemic in 2020 and 2021 has enabled the Alliances to adapt and effectively use new formats and approaches to advocate for and educate about the value of vision research.

As in past years, the NAEVR-managed mid-February Association for Research in Vison and Ophthalmology (ARVO) Advocacy Day served as an early and effective means to advocate for FY2022 funding increases of $3.2 billion for NIH to a level of $46.1 billion and $64.3 million for NEI to a level of $900 million. The requested 7.7 percent NEI increase, reflecting 2.4 percent biomedical inflation and 5.3 percent growth, is critical since its FY2021 funding increase of $12 million or 1.4 percent was less than inflation, reducing NEI's purchasing power. ARVO's advocates conducted virtual visits with 50 Congressional offices, including Members assigned to key committees with NIH funding and oversight jurisdiction, and NAEVR followed up to submit specific Programmatic Requests for NEI funding at $900 million. This activity supplements NAEVR Executive Director James Jorkasky's own direct outreach with leadership with whom he has worked through the years.

NAEVR also continued its advocacy for scientific agency research relief due to pandemic-related laboratory closures. The ARVO advocates also requested support for the *Research Investment to Spark the Economy (RISE) Act*, introduced in each the House and Senate, to authorize $26 billion for scientific agency research relief, including $10 billion for the NIH.

Under its new sustained educational program *Research Saving Sight, Restoring Vision Initiative*, AEVR continued its virtual education with the *World Glaucoma Week 2021* Congressional Briefing, featuring clinician scientist-educators Mona Kaleem, MD and Elyse McGlumphy, MD from the Wilmer Eye Institute at the Johns Hopkins University School of Medicine and patient advocate Amanda Eddy, who represented the Glaucoma Research Foundation. Since AEVR quickly toggled to virtual education in 2020, it now has a video library accessible on the Web site consisting of four Congressional Briefings and the 30-minute *Impact of COVID-19 Lab Closures on the Next Generation of Vision Scientists* reflecting a conversation with emerging vision scientists held last September.

The NEI has also been active virtually, holding its February 12 National Advisory Eye Council (NAEC) meeting—the first at which new NEI Director Michael Chiang, MD presided. The NEI announced important initiatives and new Offices that align with its in-process Strategic Plan and detailed how vision researchers have continued to successfully receive funding from NIH's BRAIN Initiative.

In closing, the Boards wish to thank all members—and our vision community—who have committed financially to supporting the Alliances in 2021. Your support throughout the pandemic in 2020 and 2021 has enabled the Alliances to adapt and effectively use new formats and approaches to advocate for and educate about the value of vision research. We look forward to working with all of you to further enhance the communications about the value of vision research and to achieve greater levels of funding for our critical work together.

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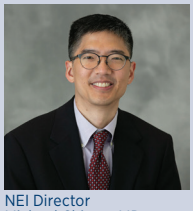
National Advisory Eye Council (NAEC) Meets



NEI Director
Michael Chiang, MD

On February 12, new NEI Director Michael Chiang, MD presided over his first NAEC meeting in which he held an interactive discussion with the Council about the planning, conduct, and follow-up to meetings. He also announced the creation of two new Offices that align with key areas within NEI's in-process Strategic Plan:

- **Office of Vision Health and Population Sciences, led by former Acting NEI Deputy Director Mary Frances Cotch, PhD**
- **Office of Data Sciences and Health Informatics, led by Kerry Goetz**

Dr. Chiang plans to develop his own narrative message about the "value of vision research" and asked vision community members to provide any data or information.

NEI also announced results of its analysis of the seventh round of new funding awards within NIH's FY2020 Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, in which the NEI is one of ten Institutes and Centers whose mission and research complements BRAIN's goals. NEI identifies vision in the retina or brain as "vision" research, and "vision-related" research includes current or past NEI grantees funded by BRAIN. Combined, these two categories received 87 new awards of the 190 new awards, competing renewals, or supplements, for a total of $113.6 million, Since funding for BRAIN began in FY2014 appropriations, "vision/vision related" research has received more than $423 million in new grant awards, competing renewals, and supplements.

NAEVR *SCORECARD* LEGISLATIVE ISSUES

FINAL FY2021

On December 27, the President signed into law the *Consolidated Appropriations Act, 2021* (H.R. 133), which included all twelve final FY2021 appropriations bills, and the accompanying *Coronavirus Response and Relief Supplemental Appropriations Act, 2021* with $900 billion in COVID-19 relief. Highlights include:

- **NIH funding of $42.934 billion, a $1.250 billion or 3 percent increase over the comparable FY2020 level, which includes $404 million for NIH through the Innovation Account for *21st Century Cures Act* initiatives.**

- **NEI funding of $835.7 million, an $11.62 million or 1.4 percent increase over enacted FY2020 funding of $824.1 million. Institutes and Centers (I/Cs) without special initiatives received this increase below the biomedical inflation rate of 2.4 percent.**

- **The COVID supplemental provides $1.25 billion overall for NIH, $1.15 billion for emergency funding for "research and clinical trials related to long-term COVID-19 studies" and $100 million for the Rapid Acceleration of Diagnostics (RADx) program, available through September 30, 2024.**

- **Neither the appropriations or supplemental portions of the bill included scientific agency relief funding for grantees due to COVID-19 lab closures.**

Although NAEVR issued a press statement expressing appreciation that the bill includes an NIH funding increase that keeps pace with inflation and emergency funding, NEI's less-than-inflationary increase means that it will need to balance funding of new competing grants with noncompeting grant out-years.

	FY2015 FINAL*	FY2016 FINAL**	FY2017 FINAL	FY2018 FINAL	FY2019 FINAL	FY2020 FINAL	FY2021 FINAL^
NIH	$30.3 B +0.5%	$32.1 B +6.6%	$34.08 B +6.2%	$37.08 B +8.8%	$39.08 B +5.4%	$41.68 B +6.7%	$42.93 B +3%
NEI	APPROP: $684.2 M +0.31% OPERATIONAL NET: $676.8 M	APPROP: $715.9 M +4.6% OPERATIONAL NET: $708 M	APPROP: $732.6 M +3.5% OPERATIONAL NET: $731.2 M	APPROP: $772.3 M +5.6% OPERATIONAL NET $770.5M	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%

* NEI Operational Net reflects $7.4 M transferred back to NIH Central of Studies of Ocular Complications of AIDS (SOCA) funding.
*** NEI Operational Net reflects $7.9 M transferred back to NIH Central of SOCA funding.
^ Does not include research relief funding for NIH grantees.

Advocacy for FY2022 NIH/NEI Appropriations, Research Relief

On March 11, President Biden signed into law *The American Rescue Plan Act of 2021* (H.R. 1319), the $1.9 trillion stimulus bill which has been the legislative focus at the start of the 117th Congress but does not provide scientific agency research relief. Democratic leaders are eager to pivot to another sweeping stimulus package addressing infrastructure, climate, health care, and numerous other priorities.

In that regard, NAEVR has joined with its advocacy colleagues in reaching out to the House Energy and Commerce (E&C) Committee and Senate Health, Education, Labor and Pensions (HELP) Committee staff to push for NIH grantee research relief in that stimulus. Both the House (H.R. 869) and Senate (S. 289) have re-introduced the *Research Investment to Spark the Economy (RISE) Act* that would authorize $26 billion for research relief for federal science agencies, including $10 billion for the NIH, to address setbacks in research due to the COVID-19 pandemic.

Although the Biden Administration's first budget has not yet issued—a "skinny" version is expected later in March—Congressional offices have set deadlines for Programmatic Requests. NAEVR is requesting:

- **NIH funding of at least $46.1 billion, a $3.2 billion or 7.4 percent increase reflecting 2.4 percent biomedical inflation plus five percent growth.**

- **NEI funding of at least $900 million, a $64.3 million or 7.7 percent increase reflecting 2.4 percent biomedical inflation and 5.3 percent growth.**

ARVO®
The Association for Research in Vision and Ophthalmology

ARVO Advocates Request FY2022 NIH/NEI Funding Increases, Research Relief

On February 19, NAEVR managed ARVO's first virtual Advocacy Day which engaged members of ARVO's Annual Meeting Planning Committee, Science Communication Training Fellows, Advocacy Awards winners, and ARVO Advocacy and Outreach Committee Chair Peter Koulen, PhD (University of Missouri, Kansas City) and Chair-elect Professor Stephanie Watson, MBBS, PhD. ARVO's domestic and international advocates made 50 calls to their Congressional delegations which included several Members assigned to key committees with NIH funding and oversight jurisdiction.

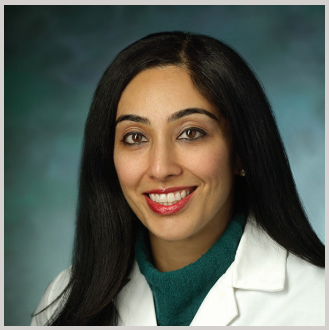
As in past years, the February date for the event meant that vision researchers were among the first advocates to request FY2022 NIH/NEI funding increases, as well as $10 million in NIH grantee research relief—supporting that request with personal accounts of the impact of COVID-19 pandemic clinical and laboratory shutdowns/slowdowns on their research.

Visit the NIH/NEI funding section of NAEVR's Web site at www.eyeresearch.org for full details

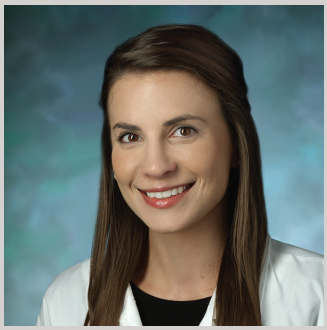
EDUCATION

AEVR Recognizes *World Glaucoma Week 2021* with a Congressional Briefing Focusing on Optimizing Patient Outcomes

RESEARCH SAVING SIGHT, RESTORING VISION
an Initiative of the
Alliance for Eye and Vision Research



Mona Kaleem, MD



Elyse McGlumphy, MD

Wilmer Eye Institute/John Hopkins University School of Medicine

On March 11, AEVR's newly launched *Research Saving Sight, Restoring Vision Initiative* held a virtual Congressional Briefing entitled *Glaucoma: Clinical Practice and Research to Optimize Patient Outcomes*. The event featured two clinician-scientist educators from the Wilmer Eye Institute at the Johns Hopkins University School of Medicine—Mona Kaleem, MD, who serves as an Associate Professor for Ophthalmology and Elyse McGlumphy, MD, who serves as an Assistant Professor for Ophthalmology—as well as patient advocate Amanda Eddy, who runs a woman-owned small business in Austin, Texas and is active with event co-sponsor Glaucoma Research Foundation (GRF).

Dr. Kaleem, who has previously participated in AEVR's *Third Annual Emerging Vision Scientists Day* held in 2017, explained how glaucoma leads to vision loss, often starting in the periphery and progressing into central vision. She described the disease's quality-of-life impact on patients, including their ability to read, walk, drive, conduct social interactions, remain independent, and have emotional well-being. She noted that reduction in IOP is the only known modifiable risk factor.

Dr. McGlumphy described how glaucoma is diagnosed after a screening eye exam through visual field testing, gonioscopy (an exam of the eye's drainage angle, the area at the front of the eye between the iris and the cornea, where fluid naturally drains out of the eye), corneal thickness measurements, and optic nerve imaging. She noted that the most common form of the disease is Primary Open Angle Glaucoma (POAG), where fluid in the eye builds up and causes damage since there is an increase in resistance to flow through the eye's fluid outflow system. This is treated by drug therapies and surgical interventions, including laser surgery or the insertion of a shunt to facilitate fluid flow. She also described Primary Angle Closure Glaucoma (PACG), a serious condition in which the eye's fluid outflow system becomes blocked, that is treated primarily by laser, surgery, and drug therapies.

Regarding research, Dr. Kaleem is focusing on creating a patient-centered system of care and trialing new treatment options, including injectable glaucoma medications and new surgical devices. She is also creating educational resources for patients and families and has joined with Harry Quigley, MD, also from Wilmer, in hosting a podcast for patients entitled Diagnosis Glaucoma, which is available with other educational materials at the Web site DiagnosisGlaucoma.com. Dr. McGlumphy, who is a guest on an upcoming episode, is focusing on surgical decision-making in glaucoma—that is, understanding the factors which influence the decision for a surgical intervention—as well as home measurement of IOP and collaborating with new companies in the development of implantable IOP sensors for continuous monitoring.

Dr. McGlumphy concluded by describing the impact of the COVID-19 pandemic on glaucoma patient care, noting an initial reduced clinical and surgical volume, with many patients lost to follow-up due to fear of attending medical appointments. Wilmer adopted various patient safety protocols and worked to individualize care for certain high-risk patients by measuring the pressure from the patient's car.

About Glaucoma

Glaucoma, the second leading cause of preventable vision loss in the United States, is a neurological disease affecting the optic nerve and causing vision loss—and ultimately blindness. It affects more than 2.7 million Americans over age 40, with that number estimated to more than double by year 2050. It includes both diagnosed and undiagnosed cases, as often individuals are unaware that they have the disease until vision is lost. Certain characteristics such as age, ethnicity, high intraocular pressure (IOP), and optic nerve structure are associated with disease development. Groups at highest risk include African Americans over age 40, individuals over age 60, and those with a family history of the disease.

Amanda Eddy,
GRF Patient Representative

In an interview with AEVR Executive Director James Jorkasky, Ms. Eddy, who currently serves as President of the Austin, Texas chapter of the Women's Jewelry Association, shared that her father went blind from glaucoma, so she was tested at three months and was diagnosed with the disease. She described her treatments—including drug therapies and surgical interventions—and her daily challenges in running a business and parenting a two-year old child. Through both laughter and tears, she related the uncertainty she faces every day regarding her vision but recognized the hope from research funded by the federal government and private funding foundations, such as GRF.

About *World Glaucoma Week 2021...*

The first *World Glaucoma Day* was held on March 6, 2008, and the United States House of Representatives passed H.R. 981, which recognized the event and supported the NEI's efforts to research the causes of and treatments for glaucoma. Since 2010, the day has expanded into a week of educational events held worldwide, with all major glaucoma professional societies and research organizations co-sponsoring AEVR's 2021 event, including:

- **Research to Prevent Blindness**
- **American Glaucoma Society**
- **ARVO (which also provided streaming support)**
- **Glaucoma Research Foundation**
- **Optometric Glaucoma Society**

AEVR's video Congressional Briefings held since mid-2020 are on the Web Site at www.eyeresearch.org

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DEFENSE-RELATED VISION FUNDING

Since it was created by Congress in FY2009 Defense appropriations by NAEVR advocacy and through FY2021, the Vision Research Program (VRP) within the Department of Defense's (DOD) Congressionally Directed Medical Research Programs (CDMRP) has been funded by Congress at $144 million and has made 118 awards for a total of $116 million, with decisions pending on the FY2020 awards (see below).

FY2020: VRP Program Committee Evaluating Proposals

On March 16, the VRP Program Committee met virtually to review the FY2020 proposals and make final funding decisions for the $20 million in funding, using three mechanisms:

- Investigator-Initiated Research Awards (IIRA, with two funding levels), with a maximum funding of $260,000 over two years/$750,000 over three years.
- Translational Research Awards (TRA), with a maximum funding of $1 million over three years.
- Focused Translational Team Science Awards (FTTSA), with a maximum funding of $5 million over four years.

The Committee recommended 17 proposals for funding. NAEVR will post abstracts of the FY2020 awards on its Web site when they are finalized and posted by the CDMRP.

FY2021: VRP Funding, Pending Program Announcement

The Consolidated Appropriations Act, 2021 (H.R. 133) signed into law by the President on December 27 included final FY2021 Defense Appropriations among the twelve spending bills. For FY2021, the VRP is funded at $20 million—the same level as in each FY2019 and FY2020.

On March 19, the VRP Program Committee held a virtual Vision Setting meeting in which NAEVR participated as a guest and during which the Committee established research goals and chose funding mechanisms for the FY2021 funding cycle. The CDMRP plans to release the FY2021 Program Announcement in the late-May timeframe, and NAEVR and ARVO are partnering to host a late-May/early-June Defense Research Webinar featuring CDMRP/VRP Program Manager Tian Wang, PhD, who will explain the FY2021 Program Announcement.

Researchers who would like to be informed about potential DOD funding opportunities should contact NAEVR's David Epstein at depstein@eyeresearch.org to be added to NAEVR's Defense Research Interest List.

FY2022: NAEVR Requests VRP Funding of $30 Million

For FY2022, NAEVR and its advocacy allies, including Blinded Veterans Association, ARVO, the American Academy of Ophthalmology, and the American Optometric Association, are requesting that Congress fund the VRP at $30 million, a $10 million increase over the $20 million funding level in each FY2019, 2020, and 2021. NAEVR justifies 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 in 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. NAEVR has begun submitting Programmatic Requests to its Congressional champions to support VRP funding at $30 million.

NAEVR Presents at Harvard Military Vision Symposium

On March 5, the Harvard Department of Ophthalmology hosted the *7th Military Vision Symposium*, with NAEVR serving as a co-sponsor. Held virtually for the first time due to the COVID-19 pandemic, the event featured a range of researchers who discussed the latest in the diagnosis and treatment of ocular trauma, as well as a discussion on future threats to vision resulting from combat operations. NAEVR's James Jorkasky presented at the symposium, providing a snapshot of eye and vision funding from federal and private sources.

Harvard plans an in-person Symposium on March 3-4, 2022.

Visit the Defense-related Vision Research section of NAEVR's Web site at www.eyeresearch.org for details

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