PRESIDENT’S MESSAGE

Thanking and Developing our Champions for Vision

Much has happened since I last wrote to you in October 2018, including the November election that resulted in new House Democratic leadership and a significant change in Congress, especially new House Members. Before year’s end, NAEVR Executive Director James Jorkasky already had plans in place for developing new champions for vision research in the 116th Congress, First Session. But we still had some important work to do—acknowledge Members who had served as our past champions.

I was fortunate to have joined Prevent Blindness last July in Washington, D.C. at the Focus on Eye Health National Summit in recognizing retiring Congressional Vision Caucus co-chairs Gene Green (D-TX) and Ileana Ros-Lehtinen (R-FL) for their service. In mid-December and before a roaring fire in the House Rules Committee offices in the Capitol, I was pleased to present a NAEVR plaque of appreciation to retiring Member Pete Sessions (R-TX). In his usual gracious manner, Cong. Sessions then engaged National Eye Institute (NEI) Director Paul Sieving, MD, PhD and the dozen participating vision community representatives in a “fireside chat” about public and private sector initiatives to accelerate translation of research into therapies for patients. It truly was an amazing discussion about the future in such an historic location.

As noted within, we are facing a third year of challenges with the President’s proposed Fiscal Year (FY) 2020 federal budget which once again would drastically cut major health programs, including the National Institutes of Health (NIH) and NEI, which are funded through nondefense discretionary (NDD) spending. As expected, NAEVR expressed concern about the proposal, noting that “We must maintain the forward momentum that Congress has driven over the past four years” of NIH and NEI funding, with increases of $9 billion and $120 million, respectively, from FY2016 through 2019.

Congress will once again have an opportunity to consider the President’s proposed cuts, which it rejected along with policy and structural changes the past two years. Critical in this regard are the Labor, Health and Human Services, and Education (LHHS) Appropriations Subcommittees of the House and Senate. We welcome Cong. Rosa DeLauro (D-CT) as the House Subcommittee Chair, and recognize the pivotal role that current Ranking Member Tom Cole (R-OK) played as prior Chair in supporting the past four years of funding increases. We also look forward to working with Senate Chair Roy Blunt (R-MO), who along with Ranking Member Patty Murray (D-WA) not only led bipartisan efforts to increase NIH funding, but also emphasized inflationary increases for the Institutes and Centers (ICs).

NAEVR has met with staff of all Subcommittee members and in some cases has been accompanied by researchers, including those participating in the February 8 ARVO Annual Meeting Planning Committee Advocacy Day. In requesting FY2020 funding increases—$2.5 billion for NIH and $53 million for NEI—the advocates acknowledged that Congress must first pass a bipartisan budget deal to raise the FY2020 and 2021 Budget Control Act caps, especially for critical NDD programs, such as medical research.

I wish to thank all members who have committed support for 2019, making the Alliances’ advocacy and educational goals possible.

Peter J. McDonnell, MD
NAEVR/AEVR Boards President
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On December 12, 2018, NEI Director Paul Sieving, MD, PhD, left, joins while Dr. McDonnell presents a NAEVR plaque to Cong. Pete Sessions (R-TX), center, who retired from Congress. Recognizing his 22 years of service in Congress—most recently as Rules Committee Chair—Dr. McDonnell called Cong. Sessions the “ultimate Friend of the NEI” for his past support for:

• Submitting Report Language that supported NEI and created the 3D Retina Organoid Challenge;
• Leading recognition of NEI’s 50th anniversary in 2018; and
• Serving as an initial co-sponsor of HR 6421, the Faster Cures and Treatment for Eye Diseases Act (Eye Bond legislation).

A number of DC-based vision organization representatives attended the event and joined Cong. Sessions in a 45-minute discussion about ways to accelerate translation of vision research into therapies for patients.

“‘We are facing a third year of challenges with the President’s proposed FY2020 federal budget.’” – Dr. McDonnell

NAEVR Events: NAEVR At The 2019 ARVO Annual Meeting

Sunday, April 28 – Wednesday, May 1
NAEVR Central, 8:30 am - 5:00 pm Daily, Vancouver Convention Center

Monday, April 29
NAEVR’s Defense-Related Vision Research Opportunities Session
7:00 am – 8:00 am, Room 109/110, Vancouver Convention Center West

AEVR Events: Congressional Briefings

Wednesday, May 15
NEI’s DRCR Network: Optimizing Treatments for Diabetic Eye Disease
12 Noon – 1:15 pm, Room 2044, Rayburn House Office Building

Wednesday, July 10
Dry Eye Awareness Month Congressional Briefing and Screening
11:30 am – 1:30 pm, Room 2043, Rayburn House Office Building

Peter McDonnell MD, William Holland Wilmer Professor and Director, Wilmer Eye Institute, Johns Hopkins University School of Medicine
World Glaucoma Week 2019
AEVR Congressional Briefing Focuses on Genetic Basis of Glaucoma

Featured speaker Louis R. Pasquale, MD (Icahn School of Medicine at Mount Sinai Hospital)

On March 6, AEVR held its World Glaucoma Week 2019 Congressional Briefing, co-hosted by all major glaucoma societies and research organizations (see box below). Entitled Understanding the Genetic Basis of Glaucoma to Develop Vision Loss Strategies, the event featured NEI-funded clinician-scientist Louis R. Pasquale, MD, who serves as a Professor of Ophthalmology at the Icahn School of Medicine at Mount Sinai Hospital and Vice Chair of Translational Ophthalmology Research for the Mount Sinai Healthcare System.

He characterized glaucoma, which is the second leading cause of preventable vision loss in the United States, as a complex neurological disease affecting the optic nerve resulting in loss of both peripheral and paracentral vision—and ultimately blindness. Certain characteristics such as age, ethnicity, and high intraocular pressure (IOP) 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. In its most common form—primary open angle glaucoma (POAG)—which affects more than 64 million people worldwide—nerve damage results from high IOP, which occurs when the fluid that circulates in and out of the front part of the eye drains inadequately. Additionally, factors aside from elevated eye pressure, such as dysregulated optic nerve blood flow and low intracranial pressure, are also being pursued as possible causes of glaucoma. NEI-funded research has resulted in several Food and Drug Administration (FDA)-approved pressure-reducing drug therapies, which have been found by the NEI-sponsored Ocular Hypertension Treatment Study (OHTS) to delay disease onset.

In addition to drug regimens, glaucoma is also treated through traditional and minimally invasive surgical techniques—many including the use of FDA-approved drainage devices to enhance aqueous humor outflow from the eye to reduce IOP. Dr. Pasquale participates in NEI’s Glaucoma Human Genetics Collaboration (NEIGHBOR) Consortium and the Glaucoma Gene and Environment Initiative (GLAUGEN) Study. These collaborative efforts, under the umbrella of a larger consortium called NEIGHBORHOOD (The NEIGHBOR Heritable Overall Operational Database), involves clinicians and geneticists at multiple institutions throughout the United States whose goal is to identify genetic variants associated with POAG in the largest and most thoroughly characterized population of people with known glaucoma status. Through mid-2018, NEIGHBORHOOD in collaboration with other large consortia throughout the world, has identified 133 genetic variants that predict within 75 percent accuracy a person’s risk for developing primary open angle glaucoma. As Dr. Pasquale noted, “Of course, more work is needed to improve this accuracy rate. But it is remarkable that recently completed research found an almost direct correlation between the magnitude of the genetic variants’ effect on eye pressure and their effect on glaucoma risk, confirming that IOP is an important factor that determines whether someone develops glaucoma.”

Among the 133 gene variants identified associated with glaucoma risk, 68 had not been previously linked to IOP, and their loci point to cellular processes, such as lipid metabolism and nitric oxide signaling, that contribute to elevated pressure. Dr. Pasquale then spoke in depth about the cellular processes, biomedical mechanisms, and metabolic pathways that not only result in elevated IOP but increase the vulnerability of the optic nerve to resulting damage. Through understanding the genetic basis of glaucoma and these concomitant pathways involved, clinicians would move even closer to making an earlier diagnosis of POAG. Furthermore, since no current treatment paradigm completely stops POAG, this genomic research may also lead to neuroprotection strategies that could potentially halt disease progression.

Dr. Pasquale concluded by commenting that, “Since I last spoke on Capitol Hill in 2014, I am pleased to report that the NEI-funded NEIGHBORHOOD Consortium has greatly expanded our understanding of the genetic basis of POAG, and that research into the associated metabolic pathways is moving us further to an earlier diagnosis of the disease and the development of effective therapies to stop its progression.”

About World Glaucoma Week 2019...
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 2019 event, including:

- Research to Prevent Blindness (RPB)
- American Glaucoma Society (AGS)
- Association for Research in Vision and Ophthalmology (ARVO)
- Glaucoma Research Foundation (GRF)
- Optometric Glaucoma Society (OGS)

In addition to speaking at the Briefing, Dr. Pasquale also visited his New York Congressional delegation in NAEVR-hosted visits.

Dr. Pasquale with Adeola Adesina, office of Senate Minority Leader Chuck Schumer (D-NY)

“Research into the associated metabolic pathways is moving us further to an earlier diagnosis of the disease and the development of effective therapies to stop its progression.” – Dr. Pasquale

Dr. Pasquale with Malika Daniels, office of Senator Kirsten Gillibrand (D-NY)
NAEVR Comments on the President’s Proposed FY2020 Budget

NAEVR supported the statement by the Ad Hoc Group for Medical Research, to which it belongs, that the President’s FY2020 budget proposal would "decimate the nation’s longstanding commitment to improving and saving lives through federal support for medical research.” Recognizing the constraints that the discretionary budget caps in place from the Budget Control Act still impose on non-defense discretionary spending, the Ad Hoc Group’s statement also urges Congress to enact “a bipartisan budget agreement that raises the discretionary spending caps and enables a robust investment in NIH in FY2020.”

NAEVR added that, “The demographics of vision impairment and blindness simply do not support federal funding for vision research moving backwards.”

House and Senate LHHS Appropriations Subcommittees Announce Hearings

Although Congress has not passed an FY2020 Budget Resolution, appropriators are proceeding with hearings, including:

Rosa DeLauro (D-CT), House LHHS Chair

April 2 Hearing with NIH Director Francis Collins, MD, PhD
April 9 Public Citizen Witness Hearing

Roy Blunt (R-MO), Senate LHHS Chair

April 11 Hearing with Dr. Collins

NAEVR will submit testimony to the hearing files and post summaries on the Web site.

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

FY2020 Appropriations: President Proposes Drastic Cuts to Non-Defense Discretionary Spending

NIH: $34.4 B  NEI: $686 M

On March 11, the White House released its FY2020 budget request for federal spending, and on March 18 it released spending details. The President proposes a total of $34.4 billion in NIH funding, a cut of $4.7 billion, or 12.1 percent, from the FY2019 funding level of $39.08 billion. This is slightly higher than the level at which NIH was funded in FY2017. It also proposes an NEI funding level of $686 million, a cut of $111 million, or 13.9 percent, to a level approximately the same at which it was funded in FY2015. In its Congressional Justification, the NEI proposes to fund 854 noncompeting research projects, a reduction of $20 million, or 13.9 percent, from the public health and research budget. As proposed in FY2019, the President’s FY2020 budget would move the Agency for Healthcare Research and Quality (AHRQ) into the NIH, renaming it the National Institute for Research on Safety and Quality (NIRSQ), and funding it at a level of $256 million. Unlike in the FY2019 proposal, the FY2020 budget would not transfer the National Institute for Occupational Safety and Health (NIOSH) or the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILR) into the NIH. In final FY2019 appropriations, Congress rejected these structural changes. In both FY2018 and FY2019, Congress also rejected proposed funding cuts and policy changes.

As is often stated, “The President proposes, the Congress disposes,” meaning that the Congress—especially the Committees that deal with appropriations—will have the final say on the FY2020 budget. And unlike the FY2019 appropriations process, the President will be negotiating federal spending with a chamber controlled by the Democratic party.

As noted in the Fall 2018 edition of this report, on September 28, 2018, the President signed the Conference Report for H.R. 6157, the “minibus” appropriations bill that combined FY2019 Defense and Labor, Health and Human Services, and Education (LHHS) spending bills that contained nearly $30 million more for vision research through a $24.2 million, or 3.1 percent increase, for NEI funding to a level of $796.5 million and Department of Defense (DOD) Vision Research Program (VRP) funding at a record level of $20 million, or a $5 million increase from the prior funding level of $15 million in each FY2017 and FY2018 (see back page). In early March 2019, Department of Health and Human Services (DHHS) Secretary Alex Azar announced a Secretary’s transfer of $385 million from the public health and research programs within DHHS, including NIH, to the Office of Refugee Resettlement. As a result, NEI’s FY2019 funding of $796.5 million has been reduced by $2.74 million to an operating level of $793.8 million. In FY2018, a similar Secretary transfer reduced NEI’s enacted funding level of $772.3 million by $1.8 million to an operating level of $770.5 million. Although NAEVR has not issued a statement on the transfer, the Coalition for Health Funding to which it belongs, that the President’s FY2020 Budget Resolution, the Ad Hoc Group’s statement also urges Congress to enact “a bipartisan budget agreement that raises the discretionary spending caps and enables a robust investment in NIH in FY2020.”

NAEVR added that, “The demographics of vision impairment and blindness simply do not support federal funding for vision research moving backwards.”

FY2019 Appropriations: NEI Budget Reduced by DHHS Secretary Transfer

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The “supergroup” meeting with key Senate Appropriations staff included Peter Koulen, PhD (University of Missouri), Mahbubul Shihan, PhD (University of Delaware), Shenandoa Toote, MD (University of Miami), Laura Friedel, Majority Staff Director for the Senate LHHS Appropriations Subcommittee, Ketaki Panse, MD (Tulane University), Sheena Song (Touro University), Erica Landis, PhD (Emory University), and Alex Keenan, Minority Staff Director for the Senate LHHS Appropriations Subcommittee.

ARVO’s 25 domestic and international advocates—including AMPC members, Advocacy and Outreach Committee members, and Science Communication Training Fellows—made nearly 40 delegation office visits, including those of new Members of the 116th Congress and members assigned to key committees with NIH funding and oversight jurisdiction. NAEVR also coordinated “supergroup” visits of the advocates with the leadership and ranking Staff Directors of the Senate LHHS Appropriations Subcommittee who wanted to hear whether the recent NIH/NEI increases were making research grant and training funding more accessible.

Reflecting on the day, NAEVR’s James Jorkasky stated, “I wish to thank ARVO Advocacy and Outreach Chair Peter Koulen, PhD (University of Missouri) for leading by example in participating in every aspect of the event. From his past experience as an advocate, he advised participants to first speak about their research and how its potential to preserve sight and restore vision provides a valuable return on investment—to the district, state, and the nation. I also wish to thank the advocates, both seasoned investigators and the Science Communication Fellows, who educated staff about the importance of training programs that develop early-stage investigators. This aspect of research is not always discussed, and it is critical to develop the next generation of vision scientists.”

NAEVR’s James Jorkasky and David Epstein were pleased to join ARVO’s Marisa Lavine, Jason Spessard, and Julene Joy in hosting the visits and taking images.
For the sixth year, RPB organized a Convening of Private Vision Research Funding Foundations with federal agencies which support vision research (NEI) and vision loss prevention research and vision surveillance (Centers for Disease Control and Prevention, CDC), as well as approve new ophthalmic drugs and devices (FDA). With a theme of *The Eye as a Window to Overall Health*, the event featured keynote presentations on the use of visual imaging to diagnose and monitor the progression of various diseases and the use of Artificial Intelligence (AI) in ophthalmology, as well as reports on collaborations between the participating foundations. NAEVR’s James Jorkasky attended and provided an update on federal funding for vision research and NAEVR’s advocacy efforts.

**ARVO and RPB Advocates Emphasize NAEVR’s FY2020 Funding Requests**

Unlike past years in which the government was still operating under a Continuing Resolution, the fact that Congress had already finalized FY2019 NIH/NEI appropriations enabled the advocates to focus on FY2020 messaging developed by NAEVR, which included:

- Thanking Congress for funding increases in FY2016 through FY2019 that increased NIH and NEI funding by a total $9 billion and $120 million, respectively.

- Requesting an NIH increase of $2.5 billion, or 6.4 percent, to a level of $41.6 billion, allowing for meaningful growth above inflation in the base budgets for the ICs, such as NEI, and ensuring funding for NIH’s Innovation Account established by the 21st Century Cures Act for special initiatives (BRAIN Initiative, Cancer Moonshot, Precision Medicine, and Regenerative Medicine).

- Requesting an NEI increase of $53 million, or 6.4 percent, to a level of $850 million. Advocates shared a graphic (see below) that showed that, despite recent increases, NEI’s FY2019 enacted budget of $797 million is just 14 percent greater than the pre-sequester FY2012 funding level of $702 million, meaning a 2 percent annual growth rate over the past seven fiscal years as compared to the 2.8 percent average annual rate of biomedical inflation.

- To enable increases, advocates also requested that Congress pass a bipartisan budget deal to raise FY2020 and FY2021 Budget Control Act (BCA) caps to fund critical nondefense discretionary programs, such as a medical research. During ARVO’s February 2018, Advocacy Day, vision researchers were among the first to thank Congress for passing the budget deal that raised FY2018 and 2019 BCA caps and facilitated an NIH and NEI funding increase in each fiscal year.

The eight participants representing seven organizations from across the nation met with 14 Congressional offices in both the House and Senate—including a number where the Member serves on a Committee with appropriations or oversight authority over the NIH. Commenting on the day’s activities, RPB President Brian Hofland, PhD said:

> **“The National Eye Institute is by far the largest funder of vision research in the U.S. Thus, one of the most important things private foundations can do to support vision research is to engage in advocacy in support of the NEI.”**

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Since it was created by Congress in FY2009 Defense appropriations by NAEVR advocacy and through FY2019, the Vision Research Program (VRP) has been funded by Congress at $104.5 million and has made 85 awards for a total of $85 million, with FY2018 awards still to be finalized.

FY2020: NAEVR Requesting VRP Funding of $20 Million

NAEVR is requesting FY2020 VRP funding at $20 million—the same level at which it was funded in FY2019 and $5 million greater than each FY2017 and 2018. NAEVR partners with the Blinded Veterans Association (BVA), ARVO, the American Academy of Ophthalmology, and the American Optometric Association in advocacy activities, supplemented by:

• The FY2020 Independent Budget (IB) requesting VRP funding at $20 million. The IB is a biennial set of recommendations to Congress regarding Department of Veterans Affairs (VA) funding which is developed by Disabled American Veterans, Paralyzed Veterans of America, and the Veterans of Foreign Wars and supported by 24 other Veterans Service Organizations (VSOs) and Military Service Organizations (MSOs), including BVA and NAEVR.

• A January 2019 Military Medicine article that estimates that deployment-related eye injuries and blindness have cost the U.S. $41.5 billion in the 2000-2017 timeframe, with $40.2 billion of that cost reflecting present value of a lifetime of long-term benefits, lost wages, and family care. The article is based on AEVR’s 2018 update of NAEVR’s 2012 Cost of Military Blindness study.

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