PRESIDENT’S MESSAGE
Let’s Make A Deal!

Peter McDonnell MD, William Holland Wilmer Professor and Director, Wilmer Eye Institute, Johns Hopkins University School of Medicine

In this classic 1960s game show, some contestants would trade a new car for “Curtain Number 3,” and often behind that was a broken-down jalopy or some other undesirable gag prize of little value. In this edition of the Report, you will read about NAEVR’s advocacy efforts—supported by AEVR’s educational efforts—that urge Congress to pass a bipartisan budget deal that raises the nondefense discretionary budget caps and enables the Senate Appropriations Committee-proposed Fiscal Year (FY) 2018 Labor, Health and Human Services, and Education (LHHS) funding bill’s $2 billion increase for the National Institutes of Health (NIH). Without this action, Congress cannot finalize the FY2018 appropriations bills as written, since they exceed Budget Control Act caps, and we could potentially end up with a full-year Continuing Resolution (CR). This would be the equivalent of the gag prize behind the curtain, as a full-year CR would essentially be a cut, due to an across-the-board reduction to meet FY2018 budget caps and the impact of inflation.

Although Congress has not yet taken visible steps to initiate a budget deal, Members of Congress from both sides of the aisle are voicing the necessity for it, especially due to numerous legislative initiatives that require funding, including additional supplemental emergency funding for the recent national disasters. As foreseen, a budget deal—ideally spanning two fiscal years—would result in Congress developing the FY2018 Labor, Health and Human Services, and Education Appropriations Committee-proposed, which may include NIH/NEI funding, policy, and structure challenges as did the FY2018 proposal. Clearly, the Alliances will remain as active as ever to ensure the greatest possible funding for eye and vision research from various federal sources.

In mid-September, I was proud to host the evening Congressional Poster Session associated with AEVR’s Third Annual Emerging Vision Scientists (EVS) Day on Capitol Hill at which NEI Deputy Director Belinda Seto, PhD spoke about the Institute’s commitment to early-stage investigators. The event, funded by a grant from Research to Prevent Blindness, drew a packed room of Members and staff interested in breakthrough research being conducted by these pre-R01 researchers. The 18 EVSs reflected the most diverse group ever along just about every metric, including the breadth of vision research. The EVSs represented many “heartland” Departments of Ophthalmology and Schools/Colleges of Optometry, which was valuable in Congressional delegation visits the next day with key Republican leaders from those states, as well as key Democrats. As in past years, several members made the time to personally visit with these early-stage investigators and hear their funding and career concerns.

I wish to thank all of the organizations that have supported the Alliances in 2017 not only with dues and contributions, but with their time and resources to assist in advocacy and education. NAEVR has held a record number of multi-researcher Advocacy Days, while AEVR has held the largest number of Congressional Briefings ever, including the greatly-expanded Dry Eye Awareness Month this past July (detailed in the Spring/Summer Report) and the upcoming Keratoconus Congressional Briefing in November (see box below)—a first-time event.

As previously noted, 2018 will likely be another tough year on Capitol Hill, even with a budget deal, due to shifting priorities and ongoing and as-yet unidentified legislative needs. But it will also be a time to celebrate NEI’s 50th anniversary, as well as AEVR’s 25th anniversary as “The Friends of the NEI.” AEVR is already planning a number of high-profile events that will draw Hill, media, and public attention to the issue of vision and vision loss. The Board-approved dues increase for each 2017 and 2018, coming after nearly ten years of no increases, have been critical in making the Alliances stronger than ever and in engaging more of the vision community than ever.

I’ll make you a deal. When the 2018 renewal issues in early December, your financial support will ensure that the Alliances continue to be prepared to deal with potential vision research funding, structure, and policy challenges that have never been greater. And we will call upon you to add your voices to the issue of vision and vision loss. NEI.” AEVR is already planning a number of high-profile events that will draw Hill, media, and public attention to the issue of vision and vision loss. The Board-approved dues increase for each 2017 and 2018, coming after nearly ten years of no increases, have been critical in making the Alliances stronger than ever and in engaging more of the vision community than ever.

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Upcoming Events:
November 7
AEVR Congressional Briefing
Spearheading Keratoconus Research: A Quest for Novel Treatments

Recognizing National Keratoconus Day 2017 (November 10)
12 Noon–1:15 pm, House Rayburn 2075

December 7
ARVO Congressional Briefing
Optical Coherence Tomography: Healthcare Savings Through Research
12 Noon – 1:00 pm, House Rayburn 2045 (AEVR serving as Co-sponsor)

And in 2018…NEI’s 50th Anniversary,
AEVR’s 25th Anniversary!

Peter J. McDonnell, MD
NAEVR/AEVR Boards President
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Left to right: Dr. McDonnell listens as NEI Deputy Director Belinda Seto, PhD speaks about NEI’s commitment to early-stage investigators at the September 13 evening Congressional Poster Session as part of the Third Annual EVS Day on Capitol Hill.

NAEVR’s advocacy outreach included Executive Director James Jorkasky (far right) speaking at the Southeastern Research Conference in Nashville, Tennessee in early October. From left, he is joined by representatives of the three sponsoring departments: Paul Sternberg, Jr, MD (Vanderbilt Eye Institute/Vanderbilt University), Chris Girkin, MD, MSPH (Department of Ophthalmology/University of Alabama at Birmingham), and Jeff Boatright, PhD (Emory Eye Center/Emory University). Together, their programs in vision research account for nearly $29 million in NEI grant funding.
**SCORECARD LEGISLATIVE ISSUES—NIH/NEI FUNDING**

As in the House, Senate Rejects Trump NIH Funding, Policy, and Structure Proposals

On September 7 and without a Budget Resolution, the Senate Appropriations Committee passed an FY2018 LHHS spending bill—approved the prior day by the Senate LHHS Appropriations Subcommittee—that totals $164.1 billion in discretionary funding for the Departments of Labor, Health and Human Services (DHHS), and Education. The bill, which is $3 billion above the FY2017 enacted level and $27.5 billion above President Trump’s budget request, provides $79.4 billion in discretionary funding for the DHHS and was described by Subcommittee Chair Roy Blunt (R-MO) and Ranking Member Patty Murray (D-WA) as a bipartisan effort—similar to that in FY2017. Details of the bill and their comparison to the House bill and President’s Trump proposal appear below:

- The $2 billion Senate-proposed NIH increase over FY2017 to $36.1 billion reflects a 1.86 billion or 5.4 percent increase to NIH base funding. The remaining $144 million of the increase reflects funding for 21st Century Cures Act initiatives, bringing its total funding within the bill to $496 million, as designated by the Act. The House’s proposed NIH funding at $35.2 billion, or an increase of $1.1 billion over FY2017, reflects an increase of $943 million or 2.8 percent on base funding. The House bill also increases Cures funding by $144 million to a total of $496 million. The President’s proposal cut NIH by $7.6 billion, or 21 percent, below enacted FY2017.
- The Senate bill funds NEI at $758.6 million, an increase of $25.9 million, or 3.5 percent, over FY2017—the second year at this percentage increase. The House bill proposed a 1.5 percent increase in NEI funding to $743.9 million. The President proposed NEI funding of $549.8 million, or a $183 million cut.
- Both the Senate and Senate bills maintain the Extramural Salary Cap at Executive Level (EL) II, while the House cuts AHRQ funding that reflects Affordable Care Act activities. The President proposed to eliminate Fogarty and move AHRQ into the NIH.
- The Senate bill directs NIH to begin a pilot program to determine the adequacy of a fetal tissue donor network for supporting all related clinical research from human fetal tissue donated solely from stillbirths and spontaneous abortion. The House bill states that none of the funds made available may be used to conduct or support research using human fetal tissue if such tissue is obtained pursuant to an induced abortion. NAEVR issued a statement expressing appreciation for the Senate’s proposed NIH funding increase, especially thanking Chairman Blunt and Ranking Member Murray for emphasizing the importance of increases for the Institutes and Centers (I/Cs), such as the NEI.

### Congress Passes CR Funding Government to December 8, House Passes “Octobus”

On September 7, the President signed Continuing Resolution (CR) legislation that funds government operations at the FY2017 level—minus an across-the-board cut of 0.68 percent—with the start of FY2018 on October 1, 2017, and through December 8, 2017. The CR contains language prohibiting DHHS from capping reimbursement of the Facilities and Administrative (Indirect) costs in an NIH grant. The legislation also raised the debt ceiling through December 8 and provided a $15.25 billion emergency supplemental funding for the federal response to Hurricanes Harvey and Irma.

On September 14, the House passed an FY2018 “Octobus” bill that combines the eight remaining individual appropriations bills, including that funding DHHS—after passing in August a “Minibus” of four appropriations bills, including those funding the Departments of Defense, Veterans Affairs and Energy, as well as the Legislative Branch. Despite the House’s efforts, this legislation will not become law due to its bills exceeding the Budget Control Act Caps for defense spending and is unlikely to pass in the Senate. NAEVR has joined with its medical research advocacy colleagues in calling for Congress to pass a bipartisan budget deal that would raise the nondefense discretionary spending caps and enable the Senate Appropriations Committee-proposed $2 billion increase in FY2018 NIH funding.

### Vision Community Members Contact Congress to Support Funding Increases

Mark Greiner, MD (University of Iowa) hosts Cong. Dave Loebsack (D-IA)

Andrew Hartwick, OD, PhD (Ohio State University College of Optometry)

On August 28, Mark Greiner, MD (University of Iowa Department of Ophthalmology and Visual Sciences) hosted Cong. Dave Loebsack (D-IA) at the Iowa Lions Eye Bank, where he serves as the Associate Medical Director. A clinician-scientist, Dr. Greiner briefed the Congressman on cutting-edge research projects addressing corneal tissue quality and availability funded by the NEI and DOD. Dr. Greiner visited Cong. Loebsack’s office in March 2017 when he spoke at AEVR’s Defense-related Vision Research Congressional Briefing on corneal transplantation, and previously visited in February 2016 while participating in the Emerging Vision Scientist track during an ARVO Advocacy Day.

**Visit the NIH/NEI funding section of NAEVR’s Web site at www.eyeresearch.org for full details**
monitor wet AMD disease progression, as well as to monitor the effect of the drug therapies to treat it. Dr. Singh acknowledged that, although dry AMD is more prevalent, no current treatments exist to restore vision in this condition. However, thanks to the NEI-funded Age-Related Eye Disease Study (AREDS) trials, an anti-oxidant regimen is available and can significantly decrease the rate of progression of dry AMD. He reported that there are also several promising therapies on the horizon for dry AMD, including retinal stem cell therapy clinical trials which are now proceeding after many years of preclinical development in animal studies. He showed how several groups have pioneered the concept of stem cell-derived retinal pigment epithelial cell transplantation in human clinical trials. He highlighted the transplantation of photoreceptor cells as a promising concept for dry AMD treatment in the future, where photoreceptors can be grown in the laboratory—essentially a “mini-retina in a dish”—and then injected into the eye to “patch” the degenerated retina in dry AMD. The goal for these transplanted cells is to make synapses—or connections—with host inner retinal neurons and regenerate the visual circuit. His most recent research has shown that these photoreceptor cells fuse with each other. He concluded by noting that stem cells hold great promise as a tool for regenerative medicine and that further progress will lead to treatments that can regenerate photoreceptors in dry AMD.

After Dr. Singh’s presentation, patient advocate Paul Gariepy offered his perspective on the impact of AMD on activities of daily living and how he is channeling his efforts through the American Macular Degeneration Foundation (see box below) to support effective treatments.

The transplantation of photoreceptor cells is a promising concept for “dry” AMD treatment in the future.

Dr. Singh discussed research activities—funded primarily by the NEI—to diagnose and treat AMD, both the “wet” or neovascular form of the disease—where new blood vessels disrupt the retina and which accounts for about 10 percent of AMD cases—as well as for “dry” or atrophic AMD, where the photoreceptors (the light-sensitive cells in the retina) and retinal pigment epithelial cells gradually die away and which accounts for 90 percent of AMD cases.

He described the dramatic improvements in wet AMD treatment from “anti-VEGF” therapy. These therapies, developed in part through NIH-funded research, include Food and Drug Administration (FDA)-approved drugs that are injected into the eye, inhibiting abnormal blood vessel growth due to Vascular Endothelial Growth Factor (VEGF) and stabilizing vision loss—and, in a proportion of cases, improving lost vision. The diagnosis of wet AMD and the efficacy of drug treatments is determined primarily by the NEI—to diagnose and treat AMD.

Representatives from new NAEVR/ AEVR member organization American Macular Degeneration Foundation (AMDF) participated in the Congressional Briefing in between visits with the Connecticut, Massachusetts, New York, and Vermont delegations.

From left: Mark Lenker (Shire), AEVR Executive Director James Jorkasky, and Scott Haber (American Academy of Ophthalmology)
AEVR’s Third Annual Emerging Vision Scientists Day on Capitol Hill

The class of the Third Annual Emerging Vision Scientists Day (see names in box below) who participated in the AEVR and NAEVR events reflecting the breadth of breakthrough vision research who were nominated by their Departments of Ophthalmology or Schools/Colleges of Optometry from across the nation.

EVS Educate About Research to Reduce Burden of Eye Disease

On September 13, AEVR’s Decade of Vision 2010-2020 Initiative hosted its Third Annual Emerging Vision Scientists (EVS) Day on Capitol Hill, which was supported by a grant from Research to Prevent Blindness (RPB). The event, held during Healthy Vision Month and International Age-related Macular Degeneration (AMD) Awareness Week 2017, was concurrent with the fifth annual Rally for Medical Research Advocacy Day (see box next page).

These 18 young investigators—reflecting the breadth of basic and clinical vision research and who have not yet received their first investigator-initiated (R01) grant from the NIH/NEI—attended AEVR’s annual AMD Congressional Briefing and displayed posters of their research in an evening Congressional Reception. On September 14 and under the auspices of NAEVR, they visited their Congressional delegation offices.

AEVR EVS Poster Reception

In addition to the poster display, AEVR President Dr. Peter McDonnell hosted a brief evening program at which NEI Deputy Director Belinda Seto, PhD offered a welcome, discussed the NIH/NEI commitment to early-stage investigators, and visited each poster. Dr. Seto was accompanied by Shefa Gordon, PhD, Acting Director of the Office of Program Planning and Analysis, and Maria Zacharias, Director of the Office of Science Communications, Public Liaison, and Education.

Since 2015, and between both the dedicated EVS Day and EVS Track at the annual ARVO Annual Meeting Planning Committee Advocacy Day, AEVR has hosted more than 80 early-stage investigators on Capitol Hill. Summaries of the 2015 and 2016 events—including brief documentary videos—are posted on the Web site at www.eyeresearch.org.

Mohamed Abou Shousha, MD (Bascom Palmer Eye Institute/University of Miami)
George Asimellis, PhD (Kentucky College of Optometry, University of Pikeville)
Hua Bi, OD, PhD (Nova Southeastern University College of Optometry)
Leah Byrne, PhD (University of Pittsburgh)
Shannon Conley, PhD (University of Oklahoma Health Sciences Center)
Asim Farooq, MD (University of Chicago)
Sapna Gangaputra, MD (Vanderbilt Eye Institute)
Elise Harb, OD (UC Berkeley School of Optometry)
Mona Kaleem, MD (University of Maryland)
Heather Livengood, PhD (New York University)
Rose Pasquale, BS (SUNY Upstate)
Rebecca Pfeiffer, PhD (Moran Eye Center/University of Utah)
James Rogala, OD (Kentucky College of Optometry, University of Pikeville)
Hajirah Saeed, MD (Mass Eye & Ear/Harvard)
Patrick Scott, OD, PhD (University of Louisville)
Dean VanNasdale, OD, PhD (Ohio State College of Optometry)
Natalia Vergara, PhD (University of Colorado)
Xiaohua (Elsa) Zhuang, PhD (Illinois College of Optometry)

Event sponsor RPB President Brian Hofland, PhD (right) with Dr. Belinda Seto
For the third year, RPB provided a grant to support the EVS events. This year, RPB Director of Communications Diana Friedman attended the events and accompanied Rose Pasquale in New York delegation visits. Ms. Friedman offered the following thoughts on her participation:

“I was pleased to spend time with the EVSs throughout the two days. They did a wonderful job of conveying their passion and expertise, which is what makes science engaging and accessible to lay people. For legislative staff and Members of Congress, getting the chance to interact with young researchers brings NIH and NEI budget discussions to life. Suddenly, these are not just numbers on a page; they represent a chance for new careers, a strong STEM pipeline, healthcare cost-savings, and of course, life- and vision-saving treatments.”

The 18 EVSs conducted 44 Capitol Hill visits, including four with Members of Congress who wanted to hear directly about their concerns as young investigators. In their meetings, the advocates thanked Congress for the $2 billion NIH increases in each FY2016 and 2017 and urged enactment of a bipartisan budget agreement that raises the non-defense discretionary spending caps to enable the $2 billion FY2018 NIH increase—to a level of $36.1 billion for the NIH and $759 million for the NEI—as approved by the Senate Appropriations Committee. Although NAEVR’s James Jorkasky and David Epstein and ARVO’s Matt Windsor, PhD accompanied many visits to obtain images, the EVSs did the talking!

**EVS Impressions/Development**

The EVS program is an important part of an early-stage investigator’s development, as noted by participants:

“The EVS program was a once-in-a-lifetime experience. While many of my research studies were funded by government, the visits and discussions with decision-makers made me feel for the first time a real connection between my research and the actions of Congress.” — Dr. Zhuang

“Thank you for allowing me to participate—it was truly one of the most rewarding professional activities I have ever had the pleasure in which to engage. It was extremely interesting to peek behind the curtain regarding policy matters on Capitol Hill.” —Dr. Rogala

“Thank you for choosing me to represent young vision scientists across the U.S. There is a lot behind the policy and funding decisions that affect us that we simply do not learn in our training. I have encouraged a couple of my colleagues to apply for the program next year.” — Dr. Kaleem

**NAEVR Sponsors Rally for Medical Research Advocacy Day**

For the fifth year, NAEVR has served as a sponsor for the Rally for Medical Research Advocacy Day, and the Rally has recognized AEVR’s International AMD Awareness Week Congressional Briefing as an official event. This year’s Rally Advocacy Day—held concurrently with NAEVR’s EVS Advocacy Day—engaged 350 advocates from 37 states in more than 250 Congressional meetings.
**WSD CONGRESSIONAL BRIEFING**

**World Sight Day 2017 Briefing Examines the Relationships Between Vision Impairment and Cognitive Decline**

On October 4, recognizing World Sight Day (WSD) on October 12, VISION 2020 USA held a Congressional Briefing entitled Vision Impairment and Cognitive Decline. A panel of four researchers and clinicians, moderated by VISION 2020 USA Chair Jeff Todd, JD (Prevent Blindness), addressed how converging epidemiologic evidence links vision impairment to risk of cognitive decline and dementia. The speakers noted that the functional challenges imposed by vision impairment are more difficult to overcome when accompanied by cognitive impairments, and vice versa.

This public health challenge is just one of several identified in a report released in September 2016 by the National Academies of Sciences, Engineering, and Medicine (NASEM, formerly the Institute of Medicine, IOM) entitled Making Eye Health a Population Health Imperative: Vision for Tomorrow. The report made nine recommendations, including calling on the Secretary of DHHS and its Centers for Disease Control and Prevention (CDC), state and local health departments, the vision community, and stakeholders to raise national awareness and take action toward reducing the burden of vision impairment and eye disease. Through the report, NASEM wants to transform vision impairments from common to rare and eliminate correctable and avoidable vision impairments in the United States by year 2030.

The 2017 WSD Briefing follows a 2016 WSD Briefing in ensuring that Capitol Hill is aware of the NASEM report and the importance of the implementation of its recommendations. AEVR was proud to be an event sponsor (see list below), and NAEVR successfully submitted Report Language to the FY2018 Senate HHHS bill that requires DHHS to report on the status of implementation of the government-related NASEM recommendations in its FY2019 Congressional Justification.

**About VISION 2020 USA**

VISION 2020 USA has been organized to better coordinate the efforts of the many US organizations working in the field of blindness prevention, both nationally and internationally. VISION 2020 USA is committed to assuring the right to sight for all peoples both within the US and countries outside the US. Launched in 2009, nearly 40 organizations have come together under the VISION 2020 USA umbrella, which is the national entity within the International Agency for the Prevention of Blindness (IAPB) and its VISION 2020: The Right To Sight initiative.

**WSD Briefing Sponsors included:**

- Alliance for Eye and Vision Research
- American Academy of Ophthalmology
- American Optometric Association
- Association for Research in Vision and Ophthalmology
- Casey Eye Institute
- Healthy Eyes Alliance
- Himalayan Cataract Project
- International Eye Foundation
- Lighthouse Guild
- Lions Clubs International Foundation
- Optometry Giving Sight
- Prevent Blindness
- Vision Impact Institute
- VisionServe Alliance

**DEFENSE-RELATED VISION FUNDING**

**Vision Research Program Funding Scorecard**

Since it was created by Congress in FY2009 in Defense appropriations through NAEVR advocacy, the Department of Defense’s (DOD) Peer Reviewed Vision Research Program (VRP) within the Congressionally-directed Medical Research Program (CDMRP) will have awarded 79 grants totaling $68.4 million (including FY2015/2016 awards). Funded at $15 million in FY2017—$5 million greater than the $10 million funding in each FY2013—2016—the CDMRP accepted full grant applications through October 25 (after a pre-proposal deadline of July 12) for two funding mechanisms: Clinical Trial Awards, with a maximum funding of $5.25 million per award, and Technology and Therapeutic Development Awards, with a maximum funding of $2.1 million per award.

The House has proposed VRP funding of $15 million in its FY2018 DOD appropriations bill, while the Senate has not marked up its companion bill. Typically, the Senate bill does not contain detailed funding for most areas of research within Defense Health Programs, but instead accepts the House’s numbers when the two bills are conferenced.

**VRP Has New Leadership**

In late September, long-time Vision Program Manager Robert Read, who had managed the VRP since its creation in FY2009 appropriations, retired. NAEVR recognized Mr. Read for his service at its Defense-Related Vision Research Opportunities session at the 2017 ARVO Annual Meeting in Baltimore. Orazio (Ray) Santullo, OD (Colonel, U.S. Air Force, Retired) now manages the VRP, having served previously as the Program Manager for the Military Operational Medicine Research Program (MOMRP) in the U.S. Army Medical Research and Materiel Command (USAMRMC) at Ft. Detrick, Maryland. Col. Santullo had previously served as the Consultant to the Air Force Surgeon General for Optometry and participated on the VRP Program Committee, on which NAEVR’s James Jorkasky and David Epstein previously served. Col. Santullo also was Chief of Optometry Services at Brooks Air Force Base in Texas.