PRESIDENT’S MESSAGE

Anticipating Change

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By the time you receive this edition of the Report—which is now a self-mailer—the elections will have been held and transition activities will be in full swing for a new Administration, including President and Department/Agency heads, and the 115th Congress, First Session. The Alliances have been building a solid foundation in anticipation of that change.

In its post-election lame-duck session, the 114th Congress still has to act on finalizing Fiscal Year (FY) 2017 appropriations, as the current Continuing Resolution (CR) expires on December 9. Anything can happen, ranging from an omnibus bill that includes a National Institutes of Health (NIH) funding increase—proposed by the Senate Appropriations Committee at $2 billion—to a full-year CR with no funding increase, unless NIH is designated as an anomaly. When the 115th Congress convenes in January, it will face the specter of FY2018 appropriations which, barring legislative action, must comply with Budget Control Act sequestration.

Most of this edition details NAEVR advocacy and AEVR education regarding the value of federal funding at the NIH and National Eye Institute (NEI). Major September events included the Second Annual Emerging Vision Scientists (EVS) Day on Capitol Hill and the Rally for Medical Research Advocacy Day. At the EVS event funded by a grant from Research to Prevent Blindness, NEI Director Paul Sieving, M.D., Ph.D. and I welcomed 22 early-stage investigators from across the nation in AEVR’s evening Congressional Reception at which they exhibited posters of their breakthrough research, then visited Congressional delegation offices the next day under the auspices of NAEVR to discuss their plight as an early-stage investigator. At the Rally Advocacy Day, both NAEVR and AEVR hosted researchers who called upon Congress to pass a short-term CR and then finalize FY2017 appropriations with the $2 billion NIH increase.

Alliance activities have been bolstered by the release of two important documents: the August 2016 JAMA Ophthalmology Online First article based on results from AEVR’s 2014 survey entitled The Public’s Attitudes about the Health and Economic Impact of Vision Loss and Eye Disease—commissioned by Research!America and conducted by Zogby Analytics through a grant from Research to Prevent Blindness. This publication, the most accessed of that edition, reported that Americans across all racial and ethnic lines rate losing vision as potentially having the greatest impact on their day-to-day life.

• The September 15 release of the National Academies of Sciences, Engineering, and Medicine (NASEM, formerly the Institute of Medicine, IOM) report entitled Making Eye Health a Population Health Imperative: Vision for Tomorrow. Released while NAEVR was hosting EVS Congressional delegation visits, the report makes nine recommendations, including calling on the Secretary of the Department of Health and Human Services (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.

NAEVR was one of nine organizations sponsoring the report (including CDC and NEI), and was pleased that the Executive Summary acknowledged the JAMA Ophthalmology article’s findings about the public’s attitudes about vision loss. NAEVR issued a statement of support for the report’s recommendations and has been engaged with fellow sponsors in discussing implementation activities. Obviously, the report provides a “rallying cry” on Capitol Hill for support for vision biomedical research and vision loss prevention research activities. In addition to the October 13 World Sight Day Congressional Briefing on the report (see back page), NAEVR joined with Prevent Blindness in meeting with staff of the four co-chairs of the Congressional Vision Caucus to discuss how they may be supportive of the recommendations. In its dissemination activities, NASEM will work with sponsors to ensure that new Members of the 115th Congress are informed about the report in first-quarter 2017. I want to thank all of the member organizations who assisted with the extensive advocacy and educational activities held in September and described herein. I especially want to thank the Ophthalmology Department Chairs and Schools/Colleges of Optometry Deans (see box below) who funded researchers to come to Washington, D.C. to describe their research and the impact of NIH/NEI funding increases on their future success. Key to training the next generation of researchers is to prepare them to describe their research and its reliance on federal funding to a public policy-oriented audience.

The renewal campaign will begin in early December, and I encourage all organizations to continue their support because the challenges have never been greater. As important as dues and contributions are to the Alliances, so are the voices of the member organizations, especially during this time of change, and we will also call upon you for assistance in that regard.

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The Alliances wish to thank Dale Heuer, M.D., Professor and Chairman, Department of Ophthalmology, and Director, Eye Institute, Medical College of Wisconsin. In the August/September timeframe, he engaged four members of his team in advocacy and education—Iris Kassem, M.D., Ph.D. and Daniel Lipinski, Ph.D. in the Emerging Vision Scientists Day; Joseph Carroll, Ph.D. in the Blue Cone Monochromacy Congressional Briefing; and Thomas Connor, Jr., M.D. in the Blinded Veterans Association’s National Convention. See details inside.
NEI/NIH Announce FY2016 Funding for Key Programs

**Audacious Goals Initiative:** On September 1, the NEI awarded $12.4 million over three years to six projects engaged in identifying biological factors that affect neural regeneration in the retina.

**Brain Research through Advancing Innovative Technologies (BRAIN) Initiative:** On October 13, the NIH announced its third round of BI awards, bringing its total FY2016 investment to just over $150 million. The awards expand NIH's efforts to develop new tools and technologies to understand neural circuit function and capture a dynamic view of the brain in action. Although the amount of FY2016 awards to vision researchers or those studying the brain through the visual route is not yet known, these researchers have done well in the first two rounds, having been awarded $31 million.

NAEVR/ARVO Host Delegations at Fourth Annual Rally for Medical Research Advocacy Day

NAEVR co-hosted the Texas delegation, which included retinal regeneration researcher Sai Chavala, M.D. (University of North Texas Health Science Center), right, bone researcher Babatunde Oyajobi, Ph.D. (University of Texas Health Science Center at San Antonio) representing the American Society for Bone and Mineral Research, left, and Lisa Hall, patient advocate for the Pulmonary Fibrosis Foundation, center.

On September 21 and just a week after NAEVR hosted 22 Emerging Vision Scientists in Capitol Hill visits (see story inside), NAEVR and ARVO co-sponsored and participated in the fourth annual Rally for Medical Research Advocacy Day. NAEVR hosted clinician-scientist Sai Chavala, M.D. (University of North Texas Health Science Center), who is an NEI-funded investigator into retinal regeneration and was nominated by NAEVR/AEVR Board Member Thomas Yorio, Ph.D. NAEVR’s James Jorkasky co-hosted the Texas delegation, while NAEVR’s David Epstein co-hosted the California delegation and ARVO’s Matt Windsor, Ph.D. co-hosted the Wisconsin delegation.

The largest and most diverse group of Rally advocates yet, the nearly 350 participants from more than 125 different organizations came together from 37 states and the District of Columbia to make more than 250 visits with Congressional offices. Researchers described their breakthroughs, while patient advocates emphasized how this emerging research is saving lives and improving the quality of life. Consistent with NAEVR’s prior message, advocates urged that Congress enact a short-term CR, then finalize FY2017 appropriations before year’s end that includes the $2 billion NIH funding increase to bring its total FY2016 investment to just over $150 million. The awards expand NIH’s efforts to develop new tools and technologies to understand neural circuit function and capture a dynamic view of the brain in action. Although the amount of FY2016 awards to vision researchers or those studying the brain through the visual route is not yet known, these researchers have done well in the first two rounds, having been awarded $31 million.

Congress Passes Short-Term CR; NAEVR Urges Final FY2017 Appropriations

On September 28, Congress passed—and the President signed on September 29—a Continuing Resolution (CR) which funds the government at the Fiscal Year (FY) 2016 level through December 9—with a roughly 0.5 percent across-the-board cut to comply with the FY2017 budget cap. It also provides $1.1 billion to combat the Zika virus.

NAEVR issued the following statement:

“NAEVR is pleased that Congress avoided the potentially disastrous impact of a government shutdown by passing this short-term CR, as the Alliance had urged in its September advocacy activities on Capitol Hill. We continue to call upon Congress to return following the election to complete FY2017 appropriations that includes the $2 billion NIH funding increase to bring its total FY2016 investment to just over $150 million, as proposed by the Senate Appropriations Committee, which reflects real growth above biomedical inflation.

Although the CR is short-term, it could still impede the progress of research, especially since it reflects a net funding level slightly below that of FY2016 during this period. As a result, grants may be approved but not funded, jeopardizing labs and their employees. In some cases, investigators may require bridge funding from private funding foundations or institution philanthropic funding to continue the momentum of research and retain trained personnel. Research does not have a ‘pause button.’”

Congress returns the week of November 14 for its post-election lame-duck session, and will have only twelve legislative days before the CR expires on December 9. It may need to pass another short-term CR in order to finalize an FY2017 omnibus spending bill, which is more likely than a series of “minibuses” that package a few bills at a time. Congress also has the option of passing a full-year CR which would not increase NIH funding unless it is designated as an anomaly and funded at a higher level than in FY2016.
EDUCATION

International AMD Awareness Week 2016 Congressional Briefing: Sustained NIH Funding Has Resulted in Successful AMD Diagnostics and Therapies

On September 14, in recognition of both Healthy Aging Month and International Age-related Macular Degeneration (AMD) Awareness Week, AEVR’s Decade of Vision 2010-2020 Initiative and co-sponsors (see box right) held a Congressional Briefing entitled Advances in the Diagnosis and Treatment of AMD and Retinal Diseases.

Clinician-scientist speaker Amir H. Kashani, M.D., Ph.D., an Assistant Professor of Ophthalmology at the USC Gayle and Edward Roski Eye Institute within the Keck School of Medicine at the University of Southern California, spoke about his clinical practice and research activities as they relate to AMD and other retinal diseases. AEVR invited Dr. Kashani—who participated in the first-ever EVS Day in October 2015—to be the featured speaker, where he addressed a packed room that included the 22 early-stage investigators who observed how their colleague described his emerging vision research to a public policy-oriented audience.

Dr. Kashani discussed research activities 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) 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, which were 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 many cases, improving lost vision. The diagnosis of wet AMD and the efficacy of drug treatments is determined in large part through the use of noninvasive imaging technology—Optical Coherence Tomography (OCT) that can show microscopic changes in the eye caused by AMD. Since OCT was also developed through NIH-funded research, he emphasized that sustained funding has resulted in both the imaging technology to diagnose and monitor wet AMD disease progression as well as the drug therapies to treat it.

Dr. Kashani acknowledged that, although dry AMD is more prevalent, no current treatments exist. 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. He specifically described a novel stem cell-based experimental therapy that is being funded by the California Institute for Regenerative Medicine (CIRM) and for which he serves as Principal Investigator. He showed how a single layer of Retinal Pigment Epithelium (RPE) cells is grown on an artificial substrate which is then injected into the eye in sheets to “patch” degenerated RPE in dry AMD.

On September 13, Monochrome Man—a non-profit patient advocacy organization that raises awareness about Blue Cone Monochromacy (BCM)—held its first Congressional Briefing about this rare genetic disease that affects males. Featured speaker Joseph Carroll, Ph.D., Co-Director of the Advanced Ocular Imaging Program at the Medical College of Wisconsin, spoke about his research into the mechanism of the disease, which is part of a consortium of investigators funded through the NEI’s Audacious Goals Initiative.

AEVR Executive Director James Jorkasky with Dawn Prall George, Executive Director of the Macula Vision Research Foundation—an event co-sponsor—and Michael Oscar, MVRF Legislative Counsel

Prior to the Briefing and under the auspices of NAEVR, Dr. Kashani met with Congresswoman Judy Chu (D-CA), with whom he had met in October 2015 during the first EVS Day.
AEVR’s Emerging Vision Scientists Day on Capitol Hill

EVSs Educate About Their Research to Reduce the Burden of Eye Disease

On September 14, AEVR’s Decade of Vision 2010-2020 Initiative hosted its Second Annual EVS Day on Capitol Hill, which was funded by a grant from Research to Prevent Blindness (RPB). The first-ever event held on October 7, 2015, was also funded by RPB and is documented in a video on the AEVR Web site.

These 22 young investigators—reflecting the breadth of basic and clinical vision research from across the nation and who have not yet received their first investigator-initiated (R01) grant from NIH—attended AEVR’s annual AMD Congressional briefing, provided on-camera interviews about their research for a summary video, and displayed posters of their research in an evening reception. On September 15 and under the auspices of NAEVR (see story right), they visited their delegation offices.

Both the educational and advocacy activities were built around one question: “How will the breakthrough research being conducted by these EVSs prevent, delay, and treat vision disorders, which will grow to an annual U.S. cost burden of $717 billion in inflation-adjusted dollars by year 2050, as projected by Prevent Blindness in its 2014 study entitled The Future of Vision: Forecasting the Prevalence and Costs of Vision Problems.

In addition to the poster display, AEVR Board President Peter McDonnell, M.D. hosted a short program at which NEI Director Paul Sieving, M.D. Ph.D. offered a welcome and discussed the NIH/NEI commitment to early-stage investigators:

“What I see looking around the room is extremely important and a lot of fun. I see the next generation of vision research and the people committed to making a difference for eye and vision health. ...The road that you have taken is an exciting one, but not an easy one since the average age of a first-time R01 (investigator-initiated) grant recipient at NIH is 42 years old. The NIH and NEI recognize that challenge and are doing something about it, for example: shorter review cycles for first-time applicants and an emphasis on funding first-time investigators; training grants, such as the K99-R00 Pathway to Independence Award; and the NIH Director’s New Innovator Award. ...We want to fund, mentor, and support the young talent here tonight.”

“Dr. Sieving spent time with each of the EVSs, including Petr Baranov, M.D., Ph.D. (Harvard University/Mass Eye & Ear) who described his research into neuroprotective growth factors in the eye.

Commenting on the Second Annual EVS Day, RPB President Brian Hofland, Ph.D. said:

“We are not only bringing emerging vision scientists to Capitol Hill for a day, we are creating policy-savvy researchers and lifelong advocates. The interactions with members of Congress underscore the importance of explaining their work to non-scientists. For something to be a funding priority, the people enacting policy decisions must be educated on what it is and why it matters. These young scientists are uniquely qualified to speak compellingly about the impact of their research and embody the value of sustained, robust, and predictable NIH funding.”

Petr Baranov, M.D., Ph.D. (Harvard University/Mass Eye & Ear)
Daniel Chao, M.D., Ph.D. (University of California San Diego/Shiley Eye Institute)
Anthony Daniels, M.D. (Vanderbilt University)
Astra Dinculescu, Ph.D. (University of Florida)
Brad Dougherty, O.D., Ph.D. (Ohio State University College of Optometry)
Michael Farkas, Ph.D. (SUNY Buffalo)
Morgan Fedorchak, Ph.D. (University of Pittsburgh)
Iris Kassem, M.D., Ph.D. (Medical College of Wisconsin)
Heather Leisy, M.D. (New York University)
Phoebe Lin, M.D., Ph.D. (Oregon Health & Science University/Casey Eye Institute)
Daniel Lipinski, Ph.D. (Medical College of Wisconsin)
Yao Liu, M.D. (University of Wisconsin-Madison)
Alexis Malkin, O.D. (New England College of Optometry)
Paula Anne Newman-Casey, M.D., M.S. (University of Michigan Medical School)
Lisa Ostrin, O.D., Ph.D. (University of Houston College of Optometry)
Dolly Ann Padovani-Claudio, M.D., Ph.D. (Vanderbilt University)
Nimesh Patel, O.D., Ph.D. (University of Houston College of Optometry)
Andrew Pucker, O.D., Ph.D. (University of Alabama at Birmingham School of Optometry)
Osamah Saeedi, M.D. (University of Maryland School of Medicine)
Mandep Singh, M.D., Ph.D. (Johns Hopkins University School of Medicine/Wilmer Eye Institute)
Luis Vazquez, M.D., Ph.D. (University of Miami/Bascom Palmer Eye Institute)
Glenn Yiu, M.D., Ph.D. (University of California Davis)
NAEVR’s EVS Advocacy Day

EVSs Request Short-Term CR, Final FY2017 Appropriations

The 22 EVSs, who conducted 50 Capitol Hill visits—including eight with Members of Congress who wanted to hear their concerns directly—urgued Congress to enact a short-term CR to keep the government funded with the start of FY2017 on October 1, and after the election recess finalize FY2017 appropriations before year’s end to include the $2 billion NIH increase, as proposed by the Senate Appropriations Committee. Within this larger request, they described their breakthrough research and why federal funding is important to their future success. NAEVR encouraged each of the EVSs to invite their Members of Congress and staff to visit their labs, as well as to serve as a resource for the office.

RPB’s Dr. Hofland participated, noting his organization’s support for early-stage investigators. Macula Vision Research Foundation (MVRF) Executive Director Dawn Prall George joined Pennsylvania Senate delegation visits. MVRF, a NAEVR/AEVR member, was a co-sponsor of the AMD Congressional Briefing. ARVO’s Matt Windsor, Ph.D. assisted NAEVR’s James Jorkasky and David Epstein in accompanying the advocates and documenting their visits.

NASEM Releases Report While EVSs Visit Capitol Hill

While the EVSs were engaged in advocacy visits, just a few short blocks away in the Washington, D.C. headquarters of the National Academies of Sciences, Engineering, and Medicine, NASEM released its report entitled Making Eye Health a Population Health Imperative: Vision for Tomorrow for which NAEVR served as a sponsor. The report presents nine recommendations to raise nationwide awareness and take action toward reducing the burden of vision impairment and eye disease. (see back page)

EVS Impressions/Development

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

“I would like to thank you for this opportunity to learn a new aspect essential to my career. After my visit, I received a really nice handwritten card from Cong. Ted Yoho (R-FL), who said that he was impressed with our Usher Syndrome research.”

-Astra Dinculescu, Ph.D. (University of Florida)

“Personally, I was quite enlightened by these visits in gaining an understanding of the nuts and bolts of how science policy and funding decisions are made at the government level. I feel that this experience helped me to better develop skills to ‘sell research’ to non-scientists who play a critical role in funding vision research.”

-Daniel Chao, M.D., Ph.D. (University of California San Diego)

“While I consider myself fairly well-educated with day-to-day politics, the hands-on experience changed many of my pre-conceived notions of the manner with which Washington works. I should also mention that the EVS program has the potential to be a career-building tool for attendees. My attendance has impressed my department and it is making university-wide news.”

-Michael Farkas, Ph.D. (SUNY Buffalo)
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) has awarded 75 grants totaling $63 million through late October 2016. Current funding status is as follows:

2015/2016: The US Army Medical Research Acquisition Activity (USAMRAA) and CDMRP are in the process of finalizing awards and are expected to issue $18.4 million from this combined funding cycle. As of late October 2016, eight FY2015/16 awards have been issued for a total of the $13.2 million, which are included in the total above.

2017: As with FY2017 NIH/NEI funding, FY2017 DOD funding has not been finalized and is currently subject to the Continuing Resolution. In May, the House Appropriations Committee passed its FY2017 Defense bill, which includes $15 million for the VRP—$5 million greater than in FY2016 and the first time at that increased level. The Senate Appropriations Committee also passed its bill in June without VRP funding. Traditionally the House takes the lead in funding many DOD Defense Health Programs and the Senate defers to its priorities when the bills are conferenced.


World Sight Day Congressional Briefing

On October 13, VISION 2020 USA’s World Sight Day 2016 Congressional Briefing focused on educating staff about the NASEM report’s nine recommendations to transform vision impairments from common to rare and eliminate correctable and avoidable vision impairments in the U.S. by year 2030.

Colonel Donald Gagliano, M.D., President of Global Medical Innovation and former Director of the Joint DOD/VA Vision Center of Excellence, with Thomas Connor, Jr., M.D. (Medical College of Wisconsin) at the BVA National Convention.

From left: Speakers included Meg McCoy, J.D., M.P.H., (NASEM), Eve Higginbotham, M.D. (Perelman School of Medicine, University of Pennsylvania) and Lori Grover, O.D., Ph.D. (King-Devick Test, Inc.). Dr. Higginbotham and Dr. Grover served on the Study Committee, while Ms. McCoy served as Study Director.

From left: Greg Chavez (The Vision Council), AEVR Executive Director James Jorkasky, and Rodney Peele, J.D. (American Optometric Association)

From left: VISION 2020 USA Chair Jeff Todd, J.D. (Prevent Blindness) with Ali Manson (American Optometric Association) and Lester Marks (Lighthouse Guild)

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