PRESIDENT’S MESSAGE

2013—A Year of Celebration, Change, and Challenge

I am pleased to communicate with you through my first President’s Message since having been elected as NAEVR and AEVR President in early March. I am both honored and humbled by the Boards’ support and realize that I have an important legacy to continue—that of Dr. Stephen Ryan. After founding the Alliances and serving as their President for 20 years, Steve stepped down in early 2013. As my first official action, I offered up resolutions unanimously adopted by each Board commending Dr. Ryan for his tireless service. (See box right)

I am excited to be leading the Alliances at such an important time in their history, as well as during their time of greatest vision research funding challenges. With this edition of the Report, we are officially starting the 20th anniversary celebration, which includes a number of events and deliverables, all of which focus on the Alliances’ message about the value of federally funded vision research. The centerpiece will be a July 9 AEVR Capitol Hill reception (see box below) featuring National Eye Institute (NEI) Director Paul Sieving, M.D., Ph.D., whom we have asked to speak about NEI’s Challenge to Identify Audacious Goals in Vision Research and Blindness Rehabilitation. In late February, I attended the NEI’s Audacious Goals Development meeting, along with several other NAEVR Board members and Executive Director Jim Jorkasky, and am excited about how this bold initiative enhances NEI’s mission of saving and restoring vision. Obviously, research funding will likely be this initiative’s greatest challenge.

Even with the leadership change, the work of the Alliances has continued unimpeded by Jim and Director of Advocacy and Education David Epstein. This Report documents their work in first-quarter 2013, which consisted primarily of advocacy with Congress to avoid the most negative impacts of the sequester, finalize Fiscal Year (FY) 2013 appropriations, and seek adequate funding for vision research in FY2014 appropriations.

Despite the medical research community’s ongoing efforts, which included NAEVR member letters to Congressional leaders and a February 7 ARVO Advocacy Day devoted to the implications for vision research, the President ordered the sequester on March 1 after Congress failed to act to avoid it. The six-month continuing Resolution (CR) that Congress passed to finalize FY2013 appropriations also contains the sequester cuts—$1.6 billion to the National Institutes of Health (NIH) and $36 million to NEI. As NIH Director Francis Collins, M.D., Ph.D. has consistently cautioned, these cuts will have their greatest impact on new grants and young investigators. He stated at a March 5 hearing of the House Labor, Health and Human Services, and Education (LHHS) Appropriations Subcommittee that, “I lament the budget’s impact on young investigators and whether they will have a career path that keeps them in research.”

That same Subcommittee, which has already begun the FY2014 appropriations process, also selected NAEVR to testify at a March 13 Public Witness hearing, along with the Coalition for Usher Syndrome Research and Helen Keller National Center—three vision groups among the 24 witnesses selected out of 150 groups that submitted requests. Wilmer’s Herrick Scholl, M.D. testified for NAEVR, which was propitious since his research focuses on retinal degenerations, including age-related macular degeneration (AMD), which Subcommittee Chair Jack Kingston (R-GA) noted was the cause of his father’s vision loss.

I do have positive spending news—the CR that finalizes FY2013 included the full House Defense bill language, meaning that the Department of Defense’s (DOD) Vision Trauma Research Program (VTRP) will be funded at the precedent-setting level of $10 million, minus the eight percent sequester cut netting $9.2 million. This funding not only partially makes up for the NEI cut, it establishes a new baseline for NAEVR’s FY2014 advocacy. NAEVR will alert the community to the Program Announcement that issues seeking grant submissions, as well as educate researchers at its May 6 Defense-Related Vision Research Opportunities Session at the ARVO Annual Meeting in Seattle.

I appreciate the commitment of time and financial support from the Alliances’ members. Feel free to email me with any comments or observations.

Peter J. McDonnell, M.D.
NAEVR/AEVR Boards President
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MARK YOUR CALENDAR

AEVR 20th Anniversary Congressional Reception
July 9, 2013 Rayburn Foyer
Featuring NEI Director Paul Sieving, M.D., Ph.D.
On February 24–26, NEI held its **Audacious Goals Development meeting.** In welcoming the more than 200 attendees, NEI Director Dr. Paul Sieving described this historic event as a “do-it-yourself meeting” with a theme of inclusiveness. “By engaging representatives from every sector of the vision community, including clinicians, researchers, private funding foundations and patient advocates, as well as government scientists and regulators from various disciplines and even entrepreneurs, this meeting will help shape the NEI research agenda to preserve and restore vision well beyond its five-year strategic plan,” he said.

NIH Director Dr. Francis Collins also spoke, urging attendees to “have a bold vision for vision” by describing NEI’s long tradition of leading in the biomedical research arena, including: working with the National Human Genome Research Institute (NHGRI) to identify more than 500 genes associated with vision loss, which is one-quarter of all genes discovered to date; the successful human gene therapy trial for patients with Leber Congenital Amarausii; and using embryonic stem cells that self-organize into a mouse eye cup as the genesis of an eye.

Discussion topics were built around the ten winning submissions from a pool of 476 entries that were selected through the NEI **Challenge to Identify Audacious Goals in Vision Research and Blindness Rehabilitation**, a unique effort conducted under the America COMPETES Reauthorization Act of 2010 that sought new and compelling scientific ideas to advance vision research from a wide and diverse audience of researchers, engineers, and “citizen scientists.” During the judging process, more than 80 experts in the vision community narrowed the field to 81 final candidate ideas, while a federal panel of 13 government clinicians and scientists chaired by Story Landis, Ph.D. (Director, National Institute of Neurological Disorders and Stroke, NINDS) made the final selection of ten winners, each of which received a $3,000 prize.

The attendees participated in a series of six breakout sessions that addressed the following topics: aging and mechanisms of disease development and progression; molecular therapy at the gene level; systems approaches to disease analysis; molecular and functional analysis and imaging of ocular tissues in vitro and in vivo; regenerative therapies for ocular disease; and vision restoration by optogenetics, small molecules, and prosthetics. For each, a working group identified goals and their feasibility and implementation, which they presented to the attendees for discussion.

**Five NAEVR board members participated in the event, in addition to Executive Director James Jorkasky:**

- President Peter McDonnell, M.D. (Wilmer Eye Institute/Johns Hopkins)
- Sally Atherton, Ph.D. (ARVO)
- Craig Crosson, Ph.D. (Medical College of South Carolina)
- John Dowling, Ph.D. (Harvard University)
- Sabri Markabi, M.D. (Alcon Laboratories/Novartis)

**Left to right: Sanford Greenberg, Ph.D. and NAEVR President Peter McDonnell, M.D., both from the Wilmer Eye Institute/Johns Hopkins University School of Medicine**

**Left to right: Malvina Eydelman, M.D. (Director of the Division of Ophthalmic and Ear, Nose, and Throat Devices within the Center for Devices and Radiological Health at the Food and Drug Administration, FDA) and Earl Smith III, O.D., Ph.D. (University of Houston College of Optometry)**

**Left to right: Wiley Chambers, M.D. (Deputy Director of the Division of Transplant and Ophthalmology Products within the Center for Drug Evaluation and Research at the FDA) and Jean Miller, M.D. (Massachusetts Eye and Ear Infirmary/Harvard Medical School)**

**Left to right: Martine Jager, M.D., Ph.D. (Leiden University Medical Center, The Netherlands) and Craig Crosson, Ph.D. (Medical University of South Carolina), a NAEVR Board member**

**Left to right: Calvin Roberts, M.D. (Bausch+Lomb), Brian Hoftland, Ph.D. (Research to Prevent Blindness) and Colonel Donald Gagliano, M.D. (Joint DOD/VA Vision Center of Excellence). Colonel Gagliano served on the federal panel that determined the winning submissions.**
President Orders Sequester

Despite intense advocacy efforts (see next page), Congress failed to act to avoid the sequester and on March 1, the President ordered the 5.1% cut to nondefense discretionary spending and eight percent cut to defense spending. This results in a $1.6 billion cut to the NIH’s $30.6 million FY2012 funding level and a $36 million cut to the NEI’s $703 million funding level.

On March 4, NIH Deputy Director for Extramural Research Sally Rockey, Ph.D. sent a letter to all signing officials at NIH-funded institutions that stated: “The Department of Health and Human Services (DHHS) and NIH are taking every step to mitigate the effects of these cuts,” but it is possible grants or cooperative agreements may be affected. The letter adds, “examples of this impact could include: not issuing continuation awards, or negotiating a reduction in the scope of your awards to meet the constraints imposed by sequestration. Additionally, plans for new grants or cooperative agreements may be re-scoped, delayed, or canceled depending on the nature of the work and the availability of resources.”

Congress Works to Finalize FY2013 Funding

On March 6 and by a vote of 267-151, the House of Representatives passed legislation (H. R. 933) that would finalize FY2013 appropriations. During the week of March 18, the Senate was working to pass its version of H.R. 933 to conference with the House prior to the current six-month Continuing Resolution (CR) expiring on March 27. H.R. 933 combines two of the FY2013 appropriations bills which the House had already finalized, the Defense and MilCon-VA bills, along with a CR that extends funding for other government agencies at the FY2012 level. However, the funding within the bill is subject to sequestration cuts, which means that the funding rate within the legislation is approximately $984 billion, the level required by the President’s sequestration order. NIH/NEI would still be subject to the sequester, noted above. For the Department of Defense’s (DOD) Vision Trauma Research Program (VTRP), the news is better. Since H.R. 933 contains the FY2013 Defense bill language passed in July 2012 that increased VTRP funding from $5 million to $10 million, the program would receive that amount, minus the eight percent sequestration cut, netting $9.2 million.

Senate Appropriators Question Administration About Sequester Impact

On February 14, new Senate Appropriations Chair Barbara Mikulski (D-MD) held a hearing on the sequester’s impact, attended by almost all 30 Committee members, which included witnesses from federal agencies. Federal Controller Danny Werfel of the Office of Management and Budget (OMB) commented that, for NIH, “there will be hundreds fewer awards” and that the sequester would “jeopardize jobs and prior research, as well as set back research into major diseases.” Despite party affiliation, Committee members expressed grave concerns about the sequester, described as a “self-inflicted wound” by Senator Mikulski and “the worst that could happen to this country outside of war,” by Senator Dianne Feinstein (D-CA). Many Senators also blamed themselves by admitting that Congress failed to take appropriate action. Although Senator Mikulski remarked that the day’s focus was the sequester, she promised that under her leadership the Senate would proceed with “regular order” bills in the FY2014 appropriations process.

House Holds FY2014 LHHS Hearings, NAEVR Testifies

On March 5 and despite Congress not yet finalizing FY2013 funding and the President not yet issuing an FY2014 proposed budget (expected April 8), House LHHS Appropriations Subcommittee Chair Jack Kingston (R-GA) presided over a hearing that included DHHS agency heads, including NIH Director Francis Collins, M.D., Ph.D., who emphasized NIH’s value in terms of public health impact and as a domestic and global economic engine. He stated that he chairs a group of research agency directors from several countries and that they have “read the U.S. playbook” in terms of investing in research. “As we go around the table, I hear about planned increases in research funding in these countries, and when it is my turn to speak, I indicate that if we are lucky, NIH will have flat funding,” he said.

On March 13, NAEVR testified at the Subcommittee’s Public Witness hearing, requesting FY2014 NIH funding at $32 billion and NIH funding at $730 million. NAEVR—which was one of 24 organizations selected out of 150 that had requested to appear—was represented by Hendrik Scholl, M.D., who serves as The Dr. Frieda Derdeyn Bambas Professor of Ophthalmology at the Wilmer Eye Institute of the Johns Hopkins University School of Medicine. Dr. Scholl, who received his medical degree in Germany and completed a fellowship in London, provided an international perspective on the importance of adequate funding. As a clinician-scientist who focuses on diseases of the retina, primarily retinal degenerations that include AMD, he cited examples of NEI’s leadership in determining the genetic basis of disease. Chairman Kingston acknowledged that his father lost his vision due to AMD.

NAEVR member organization, the Coalition for Usher Syndrome Research, was also selected to testify. Susie Trotochaud from Georgia, a parent of two children with Usher Syndrome Type 1, which is characterized by profound deafness at birth followed by blindness in early adolescence, requested the Subcommittee to encourage FY2014 NIH funding at $20 million for Usher to promote more research into the disease.
ADVOCACY

ARVO Urges Congress to Avoid ANY Funding Cuts

On February 7, members of ARVO’s Annual Meeting Program Committee participated in a National Day of Advocacy in which education, health, and medical research advocates urged Congress to avoid the looming sequester. In 40 meetings during this NAEVR-hosted event, the 13 domestic and 5 international ARVO advocates focused on the impact of the sequester on vision research funding, emphasizing that a 5.1 percent cut to NEI’s FY2012 $703 million funding would result in a loss of $36 million, or potentially 90 new research grants—any one of which has the promise to save or restore vision. They also described their research and the impact of potential cuts—from the sequester, flat funding, or reduced appropriations—as well as the effect of delayed appropriations on their research’s momentum and ability to hire and retain trained staff.

The international ARVO advocates provided global perspectives on the far-reaching impact of the U.S. biomedical enterprise, in terms of research collaborations and training opportunities. Julie Sanderson, Ph.D. (University of East Anglia, United Kingdom), who accompanied Robert Zawadzki, Ph.D. (University of California at Davis), informed the California delegation offices that the sequester would “have a global impact on research and jeopardize the United States’ leadership, as well as its ability to compete internationally.” Dr. Zawadzki, who is originally from Poland, and Ales Cvekl, M.D. (Albert Einstein College of Medicine), who is originally from the Czech Republic, provided both domestic and international perspectives in their visits.

ARVO Executive Director Sally Atherton, Ph.D., center, and Ava Bittner, O.D., Ph.D. (Johns Hopkins University/Wilmer Eye Institute), left, met with Christine Evans, office of Senator Barbara Mikulski (D-MD), who is the new Chair of the Senate Appropriations Committee.

ARVO Executive Vice President Craig Crosson, Ph.D., (Medical University of South Carolina) right, accompanied by Claudio Bucolo, Ph.D. (University of Catania, Italy) met with Catherine Phillips, office of new Senator Tim Scott (R-SC).

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While the ARVO advocates were on Capitol Hill, United for Medical Research released an updated report on the sequester’s impact on the nation’s life sciences sector, estimating that it would result in the loss of 20,555 jobs and $3 billion in economic output.

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EDUCATION

AEVR’s World Glaucoma Week 2013

Briefing Features Real-Time OCT Imaging

He stressed that structural changes in the optic nerve and retinal nerve fiber layer may be predictive of glaucoma and how Spectral Domain Optical Coherence Tomography (OCT) is valuable as a means by which to measure these changes—in comparison to baseline images for an age group or population and in relation to a patient’s own previous images. OCT, which displays a three-dimensional and cross-sectional view of the retina and not just the superficial view of its surface provided by conventional imaging technologies, enables layers of the retina to be seen and analyzed with respect to structural changes associated with glaucoma and other blinding eye diseases, such as AMD and diabetic retinopathy. To demonstrate that OCT is a non-invasive, high-speed technology, Carl Zeiss Meditec’s David Speer conducted real-time imaging of both AEVR Executive Director James Jorkasky’s eyes, the images of which were analyzed by Dr. Wollstein. Mr. Speer also conducted real-time imaging of staff members’ eyes.

“The we have come a long way in understanding glaucoma, but we still have much to learn, especially as to why it occurs disproportionately in some populations.” — Dr. Wollstein

Since the prior day the House passed a Continuing Resolution to fund the government for the remainder of FY2013 that included the 5.1 percent sequester cut and the Senate was considering its version of a bill, Dr. Wollstein impressed upon Pennsylvania delegation staff which he visited that his research is almost solely funded by NIH/NEI and could potentially be affected by budget cuts or flat funding.

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 events held worldwide, with all major glaucoma professional societies and research organizations co-sponsoring AEVR’s 2013 event, including:

- American Glaucoma Society (AGS)
- Association for Research in Vision and Ophthalmology (ARVO)
- Glaucoma Research Foundation (GRF)
- Optometric Glaucoma Society (OGS)
- The Glaucoma Foundation (TGF)

ARVO Advocates Host Members of Congress and Their Staff

On February 18, as a follow-up to the February 7 visit by Dr. Fingert during the ARVO Advocacy Day, Cong. Dave Loebsack spent the President’s holiday finding out how sequestration will hurt Iowa’s medical researchers by hosting a roundtable discussion at the University of Iowa Hospitals and Clinics (UIHC). The University could lose up to $30 million in research funding due to the federal budget cuts, and since its vision program is primarily funded by the NIH/NEI, the cuts could cause irreversible damage. “You lose the youngest minds from your group when the money is tight and you lose the most innovative projects,” said Edwin Stone, M.D., Ph.D., Director of UIHC Visual Sciences.

On February 6, ARVO Trustee Linda McLoon, Ph.D., who also serves as ARVO’s Advocacy Committee chair, had her staff host representatives of Congressman Tim Walz’s (D-MN) office. The visit resulted from a letter she had written to Cong. Walz, who is the highest ranking enlisted veteran ever to serve in Congress, thanking him for supporting increased defense appropriations for the Vision Trauma Research Program (VTPR). Dr. McLoon, who was traveling that day, commented that, “I got a call out of the blue. You never know when you send an invitation what will happen—but it is important to send an invitation to Members so that they can see your work firsthand.”

From left: Christy Willoughby, Abby McDonald and Sadie Herbert, Ph.D., who work in Dr. McLoon’s lab, along with Shawn Schloesser, Veterans Field Representative, and John Pierce, Veterans Advocate, from the office of Congressman Tim Walz (D-MN).
Both the House and Senate versions of H.R. 933 fund the Vision Trauma Research Program (VTRP) line at $10 million. Since the sequester reduces defense spending by eight percent, this would net $9.2 million. Although the highest amount appropriated in any one past fiscal year for the VTRP has been $4 million, the DOD’s Telemedicine and Advanced Technology Research Center (TATRC) which manages the program has combined years and added transferred funds to increase the net. For example, in its FY2011–2012 cycle, TATRC has awarded $14 million in awards to a total of 21 vision researchers, reflecting Congressional appropriations of $4 million in FY2011 and $3.2 million in FY2012, plus $7 million transferred over from other DOD agencies due to the quality and responsiveness of the vision grants.

“Ultimately, it was Cong. Tim Walz’s (D-MN) and Cong. Rodney Frelinghuysen’s (R-NJ) bipartisan efforts last July on the House floor to increase the VTRP from $5 million to $10 million that has made this unprecedented funding level possible,” said NAEVR Executive Director James Jorkasky. “Since the Senate’s version of H.R. 933 adopted the House bill’s $10 million VTRP line, it also sets a precedent for the Senate to establish a VTRP line and fund it at $10 million as a baseline.” Jorkasky explained that, in past years, the House defense appropriations bill specified a VTRP line while the Senate bill included vision research with other areas of research in a pool of funds, meaning that final VTRP funding was the result of conferencing two very different bills.

NAEVR anticipates that TATRC will release a Program Announcement in May. Contact NAEVR’s David Epstein at depstein@eyeresearch.org to be added to the “DOD Interest Email List” to receive updates on funding opportunities and awards.

Two Important Defense Sessions at ARVO 2013 In Seattle

  This session features prominent investigators discussing their research into Traumatic Brain Injury (TBI) and visual function in military service members and veterans.

  This session features DOD-funded investigators who will offer advice on being responsive to DOD Program Announcements.

VSOs/MSOs Support FY2014 VTRP at $10 Million

The FY2014 issue of the *Independent Budget*—an annual set of recommendations to Congress regarding Department of Veterans Affairs (VA) funding, which is developed by AMVETS, Disabled American Veterans, Paralyzed Veterans of America, and the Veterans of Foreign Wars, and supported by 54 other Veterans Service Organizations (VSOs) and Military Service Organizations (MSOs)—has once again called for increased funding for vision trauma research.

The 27th annual edition of the *Independent Budget* recommends that Congress fund the VTRP at $10 million, citing NAEVR’s 2012 Cost of Military Eye Injury and Blindness study which estimated the total projected cost to the economy resulting from combat operations from 2000 through 2010 at $25.1 billion, including the present value of future costs such as VA and Social Security benefits and lost or decreased wages. The *Independent Budget* also calls on the VA to assess the bed capacity and staffing levels in VA blind rehabilitation centers to ensure that they meet the demands of the new programs being implemented by the VA.

The Blinded Veterans Association (BVA) has sent a letter to Congressional defense appropriators also requesting FY2014 VTRP funding at $10 million. BVA was joined by signatories Paralyzed Veterans of America, Military Order of the Purple Heart USA, Inc., Veterans of Foreign Wars, Jewish War Veterans of the USA, the National Association of Uniformed Services, AMVETS, Iraq & Afghanistan Veterans of America, Vietnam Veterans of America, Military Officers Association of America, and the Association of the United States Navy.

NAEVR deeply appreciates the support of the VSOs and MSOs.

Visit the Defense-related Vision Research section of NAEVR’s Web site for more details