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AEVR is also reviewing its Congressional Briefing program for 2020, and depending on future social distancing requirements may consider Webinars for Hill staff and the vision community. In late February and in conjunction with the American Glaucoma Society’s (AGS) Advocacy Day, I had the privilege of participating in AEVR’s World Glaucoma Week 2020 Congressional Briefing, speaking about the impact of federal research funding at the NEI on glaucoma research and clinical practice. This provided an opportunity to spend the day with Alliances Executive Director James Jorkasky, who wore his “AEVR hat” during the briefing and his “NAEVR hat” while accompanying a Kellogg contingent in Michigan delegation visits.

Immediately after that event, Jim flew to London with Blind Veterans Association (BVA) President Thomas Zampieri, PhD to participate in the Blind Veterans United Kingdom’s (BVUK) Research Week. The Boards appreciate BVUK hosting Jim as he learned more about the organization entering into an agreement with BVA to conduct research jointly, as well as to garner Congressional support for a US-UK Joint Ocular Trauma Care Task Force. If implemented, the latter could potentially enable the BVUK/BVA research effort to draw upon each country’s veterans databases to result in large and statistically powerful studies about this population and the implications of vision loss. It could also potentially present additional funding opportunities for researchers.

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Michael Robinson, MD Yehia Hashad, MD

WINTER/SPRING 2020

Contributor Report

President’s Message

The Power of Biomedical Research

First and foremost, the NAEVR and AEVR Boards hope that all of you are well and staying safe as we adjust to these challenging times. The COVID-19 pandemic emphasizes the importance of biomedical research, from fundamental molecular genetics to public health and the impact of public policy on global health.

As you read this Report, which includes information through mid-April, you will see that it details Alliances activities prior to the pandemic, as well as those that have occurred as a consequence of COVID-19. What ties the pre-pandemic and current activities together is the message about the importance of biomedical research to our lives, especially now in finding an effective vaccine and treatments for this disease, as well as how that knowledge can be applied in the future to other potential pandemics and debilitating diseases. NAEVR’s messaging is one of support for all science agencies engaged in our nation’s COVID-19 response, including the National Institutes of Health (NIH) and the National Eye Institute (NEI), as Congress grapples with supplemental and Fiscal Year (FY) 2021 funding issues.

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Impact of COVID-19 on Appropriations

Congress Passes Three Supplementals, Considers Further Supplementals and FY2021 Appropriations

Prior to its Easter recess, Congress passed three supplemental packages that include additional funding for the NIH and Centers for Disease Control and Prevention (CDC) for COVID-19 vaccine development and related surveillance activities. Congress is not expected to return earlier than May 4 except to pass emergency legislation—if the House and Senate can reach agreement.

Although Congressional leaders have announced an intention to proceed with a “regular-order” appropriations process in which its passes all twelve FY2021 spending bills before the August recess, how it plans to hold Subcommittee and Committee hearings and markups remains to be determined. Although Congress has been accelerating consideration of options for remote voting and hearings, each chamber will need to consider its unique rules and the ultimate constitutionality of the actions it takes if not through on-site sessions. In an election year appropriations process in which staff had already been anticipating a Continuing Resolution (CR) or series of CRs that fund the government in FY2021 at the FY2020 level, rumors of a full-year CR are gaining traction, especially if further COVID-19 supplementalstake the majority of time. Although a CR could identify each the NIH and CDC as an “anomaly” and fund at a higher level than that in FY2020, the research advocacy community is concerned about the immediate and long-term impact on grantees and has taken the following actions:

- In March 19 and April 7 letters to Congressional leaders, the Association of American Universities, the Association of Public and Land-Grant Universities, the Association of American Medical Colleges, and the American Council on Education called on Congress to include a supplemental appropriation for major research agencies over the next four months, including the NIH, to ensure grantee funding in the research ramp-down and ramp-up activities, as well as laboratory maintenance activities. The April 7 letter requested $26 billion.

- In an April 4 letter, the Coalition for Health Funding (CHF), to which NAEVR belongs, emphasized to Congress the need for supplemental appropriations for numerous scientific agencies in light of COVID-19. Within the NIH section, CHF included an NEI example provided by Prevent Blindness as follows:

  “NEI support to address possible increased rates of myopia likely to increase due to the use of e-learning platforms and smart phone technology throughout the remainder of this school year, and potentially into the next. This would provide data necessary to address this issue and ensure children are receiving vision care during their developmental and learning years.”

- In an April 10 letter to Congressional leaders, the Ad Hoc Group for Medical Research (to which NAEVR belongs) urged Congress to limit NIH funding within the FY2021 Labor, Health and Human Services, and Education (LHHS) bill to the spending caps agreed to by Congress in the Bipartisan Budget Act of 2019. More broadly, in an April 16 letter, CHF and 370 other organizations (including NAEVR) urged Congress to exempt science and health-related agencies from the FY2021 spending caps. These letters arrived at Congress just as the House issued its “302b allocations” or top-line spending levels to its Subcommittee Chairs to begin writing the FY2021 bills.

- On April 6, Cons. Jared Huffman (D-CA), Jan Schakowsky (D-IL), and Diana DeGette (D-CO) led a letter with ten additional signatories urging Department of Health and Human Services (DHHS) Secretary Alex Azar to remove Trump Administration restrictions on NIH-funded human fetal tissue research and to “prioritize science during an unprecedented global health emergency,” arguing that NIH is unable to explore all possible options to develop vaccines and therapeutics against COVID-19. This follows the April 1 introduction of the Protecting Cures Act of 2020 (H.R. 6417) by Cons. Schakowsky and Mark Pocan (D-WI) that ensures all biomedical research tools—including fetal tissue—are available to develop vaccines and treatments against COVID-19.

NAEVR SCORECARD LEGISLATIVE ISSUES

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* NEI Operational Net reflects $16.9 M transferred back to NIH Central of Studies of Ocular Complications of AIDS (SOCA) funding.
** NEI Operational Net reflects $7.4 M transferred back to NIH Central of SOCA funding.
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On February 10, the White House released its $4.8 trillion FY2021 budget request which increases defense spending while deeply cutting that for domestic programs. The budget proposes a 9 percent, or $3.5 billion, discretionary spending cut to the DHHS, down from the $106 billion Congress provided in final FY2020. Reductions in domestic spending include the CDC (although the President has revised proposed spending upwards in light of COVID-19) and NIH/NEI, with the latter as follows:

- NIH program level funding of $38.69 billion (with $37.7 billion in discretionary budget authority for the Agency), which reflects a $3 billion, or more than a 7 percent cut, below final FY2020 funding of $41.68 billion.
- NEI program level funding of $749 million, a cut of $75 million, or 9.1 percent, below the FY2020 funding level of $824.1 million. The proposed cut would mean that NEI would be funded below its final FY2018 level.

In response to the proposed budget, NAEVR supported the Ad Hoc Group for Medical Research statement that the President’s FY2021 budget proposal would “devastate the Agency’s ability to pursue promising new science to improve and save lives.”

NAEVR Submits House Testimony Requesting NIH/NEI Funding Increases

On March 20, NAEVR submitted written testimony to the House LHHS Appropriations Subcommittee after it held its March 4 hearing with NIH Director Francis Collins, MD, PhD and several Institute Directors. NAEVR has requested:

- NIH funding at $44.7 billion, a $3 billion or 7.2 percent increase over the FY2020 funding level of $41.7 billion; and
- NEI funding of $875 million, a $51 million or 6.2 percent increase over the FY2020 funding level of $824.1 million.

NAEVR’s request, having been released in late January and used during both the February 7 ARVO Advocacy Day (see middle page) and February 26 American Glaucoma Society Advocacy Day (see far right page), is in line with the Ad Hoc Group for Medical Research’s NIH funding request, which has been endorsed by more than 340 member organizations, including NAEVR. Regarding NEI, NAEVR recognizes that despite FY2016-2020 funding increases, NEI’s FY2020 enacted funding of $824.1 million is just 21 percent greater than the pre-sequester FY2012 funding of $702 million. Averaged over those eight years, the 2.6 percent annual growth rate is still less than the average annual biomedical inflation rate of 2.8 percent, thereby eroding purchasing power.

NAEVR will submit testimony to the Senate LHHS Appropriations Subcommittee by its May 22 due date.

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

ARVO Advocates Among First to Request FY2021 NIH/NEI Funding Increases

As in past years, the early February date for the NAEVR-managed Advocacy Day associated with ARVO’s Annual Meeting Planning Committee (AMPC) meeting resulted in vision researchers being among the first advocates on Capitol Hill to request FY2021 NIH/NEI funding increases. Held on February 7, the Advocacy Day also preceded the February 10 release date of the President’s FY2021 budget proposal. The advocates were accompanied in office visits by NAEVR’s James Jorkasky and David Epstein, as well as ARVO’s Julene Joy, Erin Hering, and John Saville.

ARVO’s domestic and international advocates—including AMPC members, Science Communication Training Fellows, and ARVO Advocacy and Outreach Committee Chair Peter Koulou, PhD (University of Missouri, Kansas City)—made 40 delegation office visits, including Members assigned to key committees with NIH funding and oversight jurisdiction. They thanked Congress for passing the Bipartisan Budget Act of 2019 in July 2019—which increased both defense and nondefense spending caps for FY2020 and FY2021—as well as for Congress finalizing FY2020 appropriations in December 2019 which included funding increases of $2.6 billion for NIH and $27.6 million for NEI. The advocates requested continued, robust funding increases for FY2021, per NAEVR’s position (see left page).

Regarding NEI, the advocates described their research, highlighted potential breakthroughs, and emphasized the importance of past training grants provided by the Institute. The international advocates added their unique perspectives on the global nature of vision research, identifying their collaborations with US investigators.

The ARVO advocates included participants in its 2019-2020 Science Communications Fellows, a program managed by ARVO’s Erin Hering (far left), and represented by Ruanne Vent-Schmidt, PhD (Canadian National Institute for the Blind Foundation), Andrea Waksurnski, BS (Case Western Reserve University), Jarrod Harman, BS (LSUHC-New Orleans), Nilsu Abilgan, BA (University of Minnesota), Joshua Webb, BS (University of Maryland), Salma Ferdous, BS (Emory University), Konstantina Sampani, MD (Harvard Medical School), Amanda McLaughlin, PhD (UC Berkeley School of Optometry), and Edmund Tsui, MD (UCLA).

After Advocacy Day activities, AEVR’s James Jorkasky (far left) hosted an educational session for the ARVO participants that engaged senior representatives from the NEI. Shefa Gordon, PhD (center), who serves as the Associate Director for Science Policy, and Legislation, provided an update on key NEI programs. He was accompanied by Mary Frances Cotch, PhD (second left) who serves as the Acting Deputy Director, and Maria Zacharias (far right), who serves as Director of Science Communications, Public Liaison, and Education. ARVO’s Executive Vice President Justine Smith, PhD (second right) and Executive Director Iris Rush, CAE (third right) also participated.

Dr. Gordon announced that NEI had analyzed the awards from the sixth round of the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, which is one of the programs funded through the Innovation Account designated by the 21st Century Cures Act. For FY2019, NEI estimates that “vision” (defined as past-funded NEI investigators and researchers studying brain circuitry through the visual route) has received 80 new grants, or 44% of the 182 new grants, for a total of $93 million in new grant funding, up from $68 million in new grant funding in FY2018. The six-year total of new grant funding to “vision” from the BRAIN Initiative is more than $310 million.

The BRAIN Initiative is one of 15 programs the NEI funds through Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative— rose from $68 million in FY2018 to $93 million in FY2019, a 37% increase. This increase is due to the 21st Century Cures Act, which authorized funding for the BRAIN Initiative in FY2016. The Cures Act provided $276 million for FY2016, which increased both defense and nondefense spending caps for FY2016 and FY2017.

Regarding the NEI’s FY2019 budget, NEI Director Dr. Robert L. Greenberg noted that the NEI had been working closely with Congress on its FY2020 budget, which will be finalized in March 2019. Congress has already appropriated $1.3 billion for research in FY2019, up from $1.2 billion in FY2018.

The advocates appreciated the opportunity to share their perspectives with Congress and look forward to continuing to work with NAEVR and ARVO to advocate for increased funding for vision research.
NAEVR was pleased to work with the AGS in preparing NIH/NEI research funding messaging for its Advocacy Day, which complemented its legislative requests regarding clinical practice. The event included 74 advocates from 29 states who made 128 Congressional office visits. Dr. Lee and the Kellogg contingent visited the offices of Senators Gary Peters (D-MI) and Debbie Stabenow (D-MI), as well as Cong. Debbie Dingell (D-MI).

Research!America Releases Vision and Blindness Fact Sheet During World Glaucoma Week

On March 9, Research!America posted a blog by AEVR’s James Jorkasky that recognized World Glaucoma Week 2020 and linked to an updated Vision and Blindness fact sheet, which was supported by a grant from the Albert and Mark Lasker Foundation and prepared with AEVR’s assistance. This edition reflects the third update of the original fact sheet that issued in 2004.

Prevent Blindness Emphasizes Importance of CDC Vision Programs

At the Briefing’s end, Prevent Blindness Director of Government Affairs Sara Brown spoke after hosting patient advocates in Congressional office visits during the annual “All Eyes on Capitol Hill” Advocacy Day. Ms. Brown educated staffers about the CDC’s Vision and Eye Health Program and Glaucoma Program, especially as they inform NEI’s research initiatives.

She reported that Prevent Blindness joined with 40 other organizations, including NAEVR, in signing onto a letter to the House and Senate LHHS Appropriations Subcommittee leaders supporting FY2021 Vision and Eye Health Program funding at $5 million and Glaucoma Program funding at $4 million. The letter stated that, “The Vision and Eye Health Program has been chronically underfunded, leaving the Agency unable to update national prevalence data on the most serious eye diseases and vision impairments.”
NAEVR Participates with BVA in BVUK Research Week

In late February, BVA held its Research Week and engaged BVUK’s Dr. Renata Gomes, Chief Scientific Officer, in Capitol Hill visits with Members of Committees with jurisdiction over defense and veterans issues, as well as in visits with British Embassy senior defense staff and officials at the Walter Reed National Military Medical Center.

The following week, NAEVR’s James Jorkasky joined BVA President Thomas Zampieri, PhD in participating in BVUK’s Research Week. BVUK, founded in 1915 as St. Dunstan’s and in response to the large numbers of British troops returning from the World War I battlefields having lost their vision due to explosions or exposure to chemical weapons, is one of the Royal Family’s preferred charities. BVUK’s Research Week had two main goals—to inform senior UK officials, American Embassy London defense staff, leaders in UK vision research, and other UK-based Veterans Service Organizations about BVA and BVUK entering into an international partnership to advance interoperability between the allied military services, the US has not yet supported the US-UK Task Force; and urges the government to support this Task Force and endorse the planned Centre of Research and Innovation for Blind Veterans.”

Key to this research effort is a US-UK Joint Ocular Trauma Care Task Force, which has been recommended by UK defense officials as a means to advance ocular trauma care and research. Emerging from a 2017 Joint US-UK Task Force Charter establishing an international partnership to advance interoperability between the allied military services, the US has not yet supported the Task Force, and the respective BVA and BVUK Research Weeks in Washington, DC and London focused on obtaining support for this effort, especially with Members of Congress. Official support from both nations could potentially facilitate access to veterans databases that would support large and statistically powerful epidemiologic studies.

Regarding joint research activities, the British and American military have experienced more than a century of shared battlefield experience. This includes ocular casualty care, beginning with the early battlefield treatment guidance provided by the UK in World War I and the blind rehabilitation programs at BVUK for British and US casualties and extending to UK guidance for the first US-based vision rehabilitation programs. In that spirit of cooperation, BVA and BVUK plan to conduct a wide array of joint research activities within a Centre of Research and Innovation that draws from the US and UK veterans populations to determine needs and best practices for rehabilitation, evaluate the effect of advanced therapies and treatments, generate new solutions, and study the psycho-social impact on veterans and caregivers—all to enhance quality of life. As Dr. Zampieri has stated, “Our two nations fought together, our veterans rehabilitated together, now let’s research together.” As an example, in response to the current COVID-19 challenges, BVA and BVUK have joined efforts on the global pandemic survey open to all communities.

British Parliament Recognizes BVA’s 75th Anniversary

The Right Honorable Dr. Julian Lewis, a Member of Parliament, was joined by nearly 40 of his colleagues in the House of Commons in supporting a motion recognizing BVA’s 75th anniversary. The motion read as follows:

“The House celebrates the forthcoming 75th anniversary on March 28 of the Blinded Veterans Association of America and recognises their close and developing partnership with Blind Veterans UK (formerly St. Dunstan’s) in the area of research into sight loss; and acknowledges the unique value of the UK-US Joint Ocular Trauma Task Force; and urges the government to support this Task Force and endorse the planned Centre of Research and Innovation for Blind Veterans.”

BVA traces its roots to a March 28, 1945, meeting of World War II combat-blinded veterans who were recuperating at Avon Old Farms Convalescent Hospital in Connecticut.

NAEVR Attends Trauma Recovery Conference, Reception with Prince Harry

As part of the week’s events, NAEVR attended a conference hosted by The Royal Society and Invictus Games Foundation entitled Trauma Recovery: New Science and Technology for Mental and Physical Health. BVUK Chief Executive Nick Caplin (Major General, retired) spoke and engaged Dr. Zampieri in a panel discussion. During the meeting’s evening reception, Prince Harry, Duke of Sussex, greeted participants in one of his last official duties, as he created the Invictus Games as an international adaptive multi-sport event. First held in 2014, the Games were named after Invictus, Latin for “unconquered” and inspired by the US-based Warrior Games.

Project Gemini Reflects BVA/BVUK Partnership

Project Gemini is a joint program of BVA and BVUK that was started in 2011. Its objective is to provide veterans who have recently lost their sight with opportunities to interact with those who had previously lost sight yet are leading productive lives. During the week of activities held every May, the veterans discuss blind rehabilitation and readjustment training, adaptive technology for the blind, and the latest vision research. The highlight, however, is the opportunity to visit attractions throughout the UK and participate in tours that facilitate tactile access to items being described, such as architectural elements, armor, and jewels.

NAEVR’s James Jorkasky participated in 2012 and David Epstein participated 2015 upon BVUK’s centenary, attending a Royal Garden Party on the grounds of Buckingham Palace hosted by Sophie, Countess of Wessex, who now serves as the Official Patron.
DEFENSE-RELATED VISION FUNDING

Since it was created by Congress in FY2009, the Department of Defense’s Congressionally Directed Medical Research Programs (CDMRP) has been funded by Congress at $104.5 million and has made 96 awards for a total of $98 million, with FY2019 awards currently being negotiated.

FY2021: NAEVR Requests VRP Funding at $30 Million

NAEVR has requested FY2021 VRP funding at $30 million, an increase of $10 million over the enacted FY2020 funding level of $20 million (which was the same as in FY2019). NAEVR justifies this increase by citing the results from AEVR’s 2018 update of the Cost of Military Eye Injury study, published in the May/June 2019 edition of the journal Military Medicine, that estimated total cost from the 2000-2017 timeframe at $41.5 billion, with $40.2 billion of that cost reflecting the present value of a lifetime of long-term benefits, lost wages, and family care. Recent advocacy activities have included:

• On March 9, BVA submitted a letter to the Chairs and Ranking Members of the House and Senate Appropriations Committees requesting FY2021 VRP funding at $30 million, supporting NAEVR’s request. The letter was signed by 25 other Veterans Service Organizations (VSOs) and Military Service Organizations (MSOs), including BVUK.

• On April 14, the Defense Health Research Consortium (DHRC), a coalition (including NAEVR) of advocacy groups and universities which support DOD Health Programs, sent letters to the Chairs and Ranking Members of the House and Senate Defense Appropriations Subcommittees requesting FY2021 increases for research funded by the DOD/CDMRP, including the VRP. The letter emphasized that the CDMRP’s innovative research portfolio fuels scientific discovery by funding high impact research not sponsored by the NIH, the Department of Veterans Affairs (VA), and other federal agencies. It included a document listing many examples of the important advances that have resulted from DOD research programs, including those in the vision space funded by the VRP. NAEVR, BVA, and the American Academy of Ophthalmology were signatories on the letter.

FY2020: VRP Program Committee to Release Program Announcement

For FY2020, the VRP will have $20 million, the same amount as FY2019. On April 1, the VRP Program Committee held a Vision Setting Web meeting in which NAEVR participated as a guest and during which the Committee established research goals and chose funding mechanisms for the FY2020 funding cycle. The CDMRP plans to release the FY2020 Program Announcement in the late-May timeframe, and NAEVR and ARVO are partnering to host a May 19 Defense Research Webinar featuring CDMRP/VRP Program Manager Tian Wang, PhD, who will explain the FY2020 Program Announcement (see front page box).

FY2019: VRP Program Committee Evaluating Proposals

On March 31, the VRP Program Committee held a Web meeting to review grant proposals and finalize decisions on which projects to fund in the FY2019 funding cycle using three funding mechanisms:

• Focused Translational Team Science Award (FTTSA), with a maximum funding of $5 million over four years

• Investigator-Initiated Research Award (IIRA), with two separate funding levels: Level 1, with a maximum funding of $260,000 over two years; and Level 2, with a maximum funding level of $500,000 over three years

• Translational Research Award (TRA), with a maximum funding of $750,000 over three years

BVA Hosting November 2020 Veterans Day Events

The BVA will host the November 11 Veterans Day 2020 Wreath-Laying event at Arlington Cemetery—the first time for a vision-related veterans group to serve in this capacity. BVA will host a reception of VSOs, MSOs, dignitaries, and sponsors (which includes NAEVR) at a reception at Ft. Myer, Virginia. Stay tuned for more details.