President’s Message
Congressional Resolutions Affirm NEI’s Leadership of Nation’s Vision Research Commitment

Last edition, I reported on the significant NAEVR presence on Capitol Hill that facilitated more than $200 million in funding for vision researchers from the National Eye Institute (NEI)~$174 million in American Recovery and Reinvestment Act (ARRA) funding from the $10.4 billion for the National Institutes of Health (NIH) and $21.4 million in increased Fiscal Year (FY) 2009 appropriations—and the Department of Defense (DOD). Regarding the latter, the DOD so values vision research that it has added $1.2 million to the $4 million Congressional appropriation to fund its FY2009 Vision Research Program, an announcement for which recently issued. NAEVR is using that fact to support its FY2010 request for $10 million for this dedicated line item in defense appropriations.

In this edition, NAEVR reports on its activities to increase vision research funding, as well as Capitol Hill efforts to acknowledge the NEI’s 40th anniversary and garner support for the designation of 2010–2020 as the Decade of Vision. The NEI began its celebration in early April—upon the 40th anniversary of the first meeting of the National Advisory Eye Council (NAEC)—with a series of campus-based events highlighting its leadership in basic, translational, and trans-Institute collaborative research. I was fortunate to have been a speaker for the excellent April Genetics and Genomics Symposium. NEI’s commitment to the genetic basis of eye disease not only facilitates prediction, preemption, and treatment, but keeps it within the focus of NIH Director-designate Francis Collins, M.D., Ph.D., former director of the Human Genome Project. Dr. Collins and NEI Director Paul Sieving, M.D., Ph.D., have collaborated closely in the past, and we look forward to Dr. Collins’ confirmation. We thank Acting NIH Director Raynard Kington, M.D., Ph.D., for his dedicated service.

I was in Washington, D.C., for AEVR’s June 17 reception celebrating the NEI’s 40th anniversary on Capitol Hill, which drew more than 200 attendees. Just the previous day, the House unanimously passed H. Res. 366 acknowledging the NEI’s 40th anniversary and designating the Decade of Vision. Lead Republican co-sponsor Cong. Pete Sessions (R-TX) and co-sponsor Gene Green (D-TX), who co-chairs the Congressional Vision Caucus, attended the reception and made compelling comments, much as they did the previous day (with lead Democratic sponsor Cong. Tammy Baldwin, D-WI) on the House floor, which have been documented in the Congressional Record.

The resources put into the successful passage of these Congressional resolutions will have long-term benefits, as they have detailed the value of vision research—past, present, and into the future.

After reading the statements, I have never felt prouder of the NEI’s accomplishments, and I encourage you to download the document from NAEVR’s Web site. On July 7, the Senate passed its companion resolution, S. Res. 209, and we also thank lead Republican sponsor Senator Johnny Isakson (R-GA) and lead Democratic co-sponsor Ben Cardin (D-MD) for their efforts.

Alliance members should realize how difficult it is in the current Congress to not only get resolutions passed in both chambers, especially the Senate, but to get them acted upon in such a short timeframe and in a strong bipartisan manner. I am proud of NAEVR/AEVR Executive Director James Jorkasky and NAEVR Advocacy Manager David Epstein for their success in this regard, which testifies to their strong working relationships with Members from both sides of the aisle. I would be remiss if I did not also acknowledge the American Academy of Ophthalmology (AAO), the Association for Research in Vision and Ophthalmology (ARVO), and Prevent Blindness America (PBA) for their assistance with key Members, as well as all of the NAEVR network members who urged their Representatives to sign onto H. Res. 366 as co-sponsors.

The resources put into the successful passage of these Congressional resolutions will have long-term benefits, as they have detailed the value of vision research—past, present, and into the future. As Congress considers future NIH funding vis-à-vis ARRA and past appropriations, it is hungry for examples of how medical research investment is saving and improving lives. At this strategic time, NAEVR has provided cogent examples of how the vision research investment can reduce healthcare costs, increase productivity, and improve the quality of life.

I want to thank all 2009 NAEVR/AEVR contributors. As you can see, the Alliances are strong and productive and continue to be among the most effective in advocating and educating about the value of research.

Stephen J. Ryan, M.D.
President, NAEVR/AEVR Boards
sryan@doheny.org
Significant Developments in Defense-Related Vision Research Funding

DOD’s TATRC Announces FY2009 Vision Research Program Funded at $5.2 Million

On July 1, the Department of Defense’s (DOD) Telemedicine and Advanced Technology Research Center (TATRC), which is managing the $4 million Peer Reviewed Research-Vision line item included in FY2009 Defense appropriations, released its Vision Research Program (VRP) Announcement. TATRC has added $1.2 million of its own funding to the $4 million Congressional appropriation for an FY2009 VRP funding total of $5.2 million. TATRC estimates that 10 grants will be funded, although that will vary based on the submitted proposals. Proposal submission is a two-step process, with the pre-proposal deadline of July 30, 2009, and full proposal deadline of October 22, 2009. TATRC anticipates funding notifications to issue in February 2010. NAEVR (Executive Director James Jorkasky and Advocacy Manager David Epstein) and ARVO (Executive Director Joanne Angle) serve as Consumer Advocates to the TATRC Program Review Panel.

NAEVR Hosts Key DOD Representatives in ARVO Annual Meeting Session

On May 4, NAEVR hosted a standing room-only Defense-related Vision Research Briefing which featured Robert Read, TATRC Senior Project Officer, who spoke about the impending Vision Research Program Announcement (see above), and Colonel Donald Gagliano, M.D., Director of the Vision Center of Excellence (VCE). Although Dr. Gagliano emphasized that the VCE will not be funding research, the Military Eye Trauma Injury Registry it is charged with developing will assist in identifying future DOD vision-related research needs. Dr. Gagliano also serves on the TATRC Program Review Panel.

NAEVR Supports $10 Million for Vision in FY2010 Defense Appropriations

On July 10, NAEVR made a last round of visits to members of the House Defense Appropriations Subcommittee, prior to markup of its FY2010 Defense appropriations bill, requesting support to maintain the dedicated Peer Reviewed Medical Research-Vision line item and increase its funding to $10 million. NAEVR was joined by Specialist Travis Fugate, USA (retired), who was blinded in Iraq and testified in a March 2009 House Veterans Affairs Committee hearing about the aftermath of his injuries. NAEVR justified the line item increase with the following new data:

TATRC’s addition of $1.2 million of its own funding to the $4 million FY2009 Congressional appropriation (see above).

Total FY2008 funding for vision in DOD’s Congressionally Directed Medical Research Program (CDMRP) is $6 million, or about 12 percent of the $50 million pool of funds.

DOD Traumatic Brain Injury Research Program Opens for Pre-Proposal Submission

On July 10, DOD/CDMRP released the Program Announcement for the FY 2009 Psychological Health/Traumatic Brain Injury (PH/TBI) Research Program. The program is funded at $40.6 million, with an emphasis on research to prevent, mitigate, and effectively treat TBI. Pre-proposal submissions are due by August 14, 2009, with full submission due by October 28, 2009.

Visit NAEVR’s Web site for full details.
Legislative Scorecard Issues

FY2010 NIH/NEI Appropriations Summary

Despite the two-year ARRA funding for NIH of $10.4 billion ($174 million for the NEI), medical research advocates are urging Congress to increase NIH funding by at least seven percent in FY2010 to restore NIH purchasing power lost due to flat funding and biomedical inflation over the past six funding cycles.

President Proposes 1.4 Percent NIH Increase, House LHHS Bill Proposes 3.1 Percent

On May 7, President Obama released his FY2010 budget, which proposes to increase NIH funding by $443 million, or 1.4 percent, over the FY2009 level of $30.03 billion (net of transfers). NEI funding would increase by $7.3 million, or one percent, over the FY2009 level of $688.5 million. The NEI is among a number of Institutes/Centers (ICs) with a minimal increase, due to the President’s focus on cancer and autism research.

In a May 21 Senate Labor, Health and Human Services, and Education (LHHS) Appropriations Subcommittee hearing with Acting NIH Director Raynard Kington, M.D., Ph.D., Chairman Tom Harkin (D-IA) expressed concern about the President’s budget, in terms of the adequacy of the NIH increase as well as the majority of that increase being directed to cancer and autism research. Dr. Kington responded that NIH will work within the budget given to it by Congress, that cancer and autism research often is funded out of various ICs, and that cancer research can elucidate complex biological pathways applicable to all disease research.

House Appropriations Chair (and LHHS Appropriations Subcommittee Chair) David Obey (D-WI) has been even more vocal in his concern over the Administration’s targeted funding. He expressed his concerns in a June 2 hearing with Secretary of Health and Human Services Kathleen Sebelius. He followed that up with a July 10 statement accompanying the LHHS Subcommittee markup of its bill in which he stated that it “rejected the Administration’s targeted funding approach and ensured that all ICs receive funding to offset biomedical research inflation.” The House bill would increase NIH funding by $941.8 million, or 3.1 percent increase, over FY2009, and a $500 million increase over the President’s request. NEI would be funded at $713.1 million, a 24.6 percent, or 3.56 percent increase, over FY2009. NAEVR commended Chairman Obey for improving upon the President’s budget and making an initial step to stem inflationary losses, stating that it looked forward to working with the Senate and in any subsequent conference to stem inflationary losses and re-build the NIH base.

The Senate LHHS Subcommittee is expected to mark up its bill in late July.

ARVO Members Contact Congress, Urge at Least Seven Percent FY2010 NIH/NEI Increase at 2009 ARVO Annual Meeting

On July 8, President Obama nominated Francis Collins, M.D., Ph.D., as the 16th Director of the NIH. NAEVR applauded this move, noting Dr. Collins’ impressive record as a scientist and leader, having served as Director of the Human Genome Project and National Human Genome Research Institute (NHGRI). NAEVR also cited Dr. Collins’ past collaborative efforts with NEI on ocular genetics, resulting in one-quarter of all genes discovered to date being associated with vision impairment and eye disease.
Inaugural NEI 40th Anniversary Event Features Blind Mountain Climber

On April 3, the NEI initiated a series of events to celebrate its 40th anniversary, in which NAEVR and several network members participated. The NIH campus-based event, hosted by NEI Director Dr. Paul Sieving, featured blind mountain climber Erik Weihenmayer, who was visually impaired at birth by a genetic eye condition called retinoschisis and completely blind by age 13. Weihenmayer spoke and premiered his film Blindlight, which documented how he, his team, and six blind Tibetan teenagers journeyed up the north face of Mount Everest.

The program also featured groundbreaking technology being supported by the NEI that uses the tongue to get visual signals to the brain. BrainPort, developed by Madison, Wisconsin-based Wicab, Inc., uses a camera mounted on a person’s head to send electronic signals to a small, flat surface attached to a person’s tongue. The tongue then sends visual cues to the brain that includes sizes, shapes, and relative distances. Michael Oberdorfer, Ph.D., who serves as the NEI’s Director of the Strabismus, Amblyopia and Visual Processing, and Low Vision and Blindness Rehabilitation Programs, described the technology’s ability to employ the “plasticity of the brain” in seeking other avenues to obtain and process information, such as sensory substitution used for other systems such as Braille. BrainPort, which requires training the brain incrementally using daily practice sessions, has been under development for about 12 years, with Food and Drug Administration (FDA) approval pending.

Weihenmayer noted that he has been involved for about five years in testing the BrainPort device and providing user feedback. “I thought it was cool how quickly my brain caught on to what I was feeling with my tongue,” he said.

NAEVR Supports House and Senate Resolutions Acknowledging NEI 40th Anniversary

Since it serves as “The Friends of the NEI,” NAEVR worked with its bipartisan House and Senate champions to secure resolutions that acknowledge the NEI 40th anniversary and support the designation of 2010-2020 as the Decade of Vision.

On June 16, the U.S. House of Representatives unanimously passed H. Res. 366. During House floor debate, lead Democratic sponsor Cong. Tammy Baldwin (D-WI) and original Republican co-sponsor Cong. Pete Sessions praised the accomplishments of the NEI in saving and restoring vision. Cong. Gene Green, resolution co-sponsor and co-Chair of the Congressional Vision Caucus, echoed that support, noting that the country’s vision health challenges will increase significantly in the next decade due to the aging of the population and the disproportionate increase of eye disease in fast-growing minority populations. In total, there were 114 co-sponsors for the bill. Cong. Baldwin and Cong. Sessions each issued press releases acknowledging passage.

On July 7, the Senate passed S. Res 209. The lead Republican sponsor was Senator Johnny Isakson (R-GA) and the original Democratic co-sponsor was Senator Ben Cardin (D-MD).

NAEVR urges the vision community to read the Congressional Record which documents the compelling statements made by Congs. Baldwin, Sessions, and Green, each of which provides a different perspective on the important role that NEI serves in preventing blindness and saving and restoring vision. The statements also commend NAEVR for its efforts to expand awareness of the incidence and economic burden of eye disease.
H. Res. 366 Passes as Vision Community Recognizes NEI 40th Anniversary on Capitol Hill

On June 17, AEVR hosted a Capitol Hill reception recognizing the NEI’s 40th anniversary, which brought together more than 200 attendees representing Members of Congress and their staffs, the vision community, and coalition partners. The event came one day after passage of H. Res. 366 (see previous page). Future AEVR educational events will be held under the DOV banner, which represents a sustained program to educate about the value of federally funded vision research.

While speakers acknowledged the rich history associated with the founding of the NEI, they also focused on current research to save and restore vision and its global impact. AEVR Board President Dr. Stephen Ryan recognized the important role of vision community organizations Research to Prevent Blindness (RPB) and the Lions Clubs in advocating for the creation of a free-standing eye institute separate from the then-National Institute for Neurological Diseases and Blindness. These efforts, which began in the mid-1960s, culminated in passage of the NEI Act that was signed into law by President Johnson in 1968. The NEI held the first meeting of its National Advisory Eye Council (NAEC) in April 1969. Dr. Ryan announced that the 122nd meeting of the NAEC would be held the next day and that several NAEC members were present that evening. RPB and Lions Clubs were just two of the 18 vision community organizations that submitted congratulatory letters to the NEI, which were displayed at the event.

Dr. Ryan acknowledged the leadership of NEI’s first director, Carl Kupfer, M.D., who served for more than 30 years, and Edward McManus, who served for more than 25 years as NEI Deputy Director and subsequently as AEVR Executive Director. Dr. Ryan recognized current NEI Director Dr. Paul Sieving’s commitment to NEI’s leadership in basic, clinical, and epidemiological research and as a proactive collaborator with other NIH Institutes and private funding foundations. In his comments, Dr. Sieving emphasized NEI’s leadership in the study of the genetic basis of eye disease, highlighting the measurable vision improvement within the initial safety trials of a human gene therapy trial that NEI has funded with the Foundation Fighting Blindness (FFB) on Leber Congenital Amaurosis (LCA), a rapid retinal degeneration that blinds infants in their first year of life.

Lions Clubs International President Al Brandel, a retired police detective from Long Island who has served as a Lion for 35 years, concluded the program by emphasizing the global impact of NEI’s research. Lions Clubs International programs have helped to preserve vision in more than 40 million individuals. “We were there for the creation of the NEI, and we will continue our partnership with the NEI in the future to save and restore vision worldwide,” he said.

Commenting on the passage of H. Res. 366 and the reception, AEVR Executive Director James Jorkasky stated that, “These recent events underscore the importance that Congress places on the NEI as the nation’s lead institution within the NIH to prevent blindness and save and restore vision. James Jorkasky

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On April 27-28, the NIH’s Scientific Management Review Board (SMRB) held its initial meeting. Composed of representatives from the NIH and the science community, the SMRB was established by the NIH Reform Act of 2006 [P.L. 109-482] to advise on NIH structural changes. The SMRB is to issue a report of its recommendations not less frequently than once each seven years, and must meet at least five times before issuing a report.

Although the SMRB’s focus was on two major agenda items—a potential merger of the National Institute on Drug Abuse (NIDA) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) and potential changes to the NIH Intramural Research Program—the Board first heard from two past NIH Directors, Harold Varmus, M.D., who currently serves as the President of the Memorial Sloan-Kettering Cancer Center, and Elias Zerhouni, M.D., who currently serves as Senior Fellow-Global Health at the Bill & Melinda Gates Foundation.

In March 2001, Dr. Varmus proposed that NIH be reorganized into six comparably sized units, five of which would be organized along groups of diseases (often called “clusters”), as well as the Office of the Director. In his SMRB comments, Dr. Varmus recognized that numerous steps had already been taken through the 2006 reauthorization and administratively within NIH to foster trans-Institute research.

The SMRB also heard from scientists who participated in the development of the last major report on the structure of the NIH—the National Research Council/Institute of Medicine report entitled Enhancing the Vitality of the NIH: Organizational Change to Meet New Challenges, which issued in 2003. The IOM report rejected Dr. Varmus’ proposal to cluster Institutes, but did note that an NIDA/NIAAA merger could potentially make sense, especially if research efforts to understand the basis of addiction were better coordinated. When the SMRB addressed this issue at the meeting, it encouraged public comment, hearing from several professional societies and patient groups, which overwhelmingly opposed the merger, especially since the NIDA has not usually focused on end-target organ research, such as liver research funded by the NIAAA.

The SMRB also discussed a number of recommendations that have been made regarding changes to the Intramural Research program, from the 2003 IOM report and earlier that morning from Dr. Zerhouni.

The SMRB proposed to organize three Working Groups dealing with: “Deliberating Organizational Change” (underlying principles guiding SMRB recommendations); the proposed NIDA/NIAAA merger; and changes to the Intramural Research program. The SMRB planned to meet next in September.

NAEVR is monitoring SMRB actions closely, since legislative drafts of what ultimately was passed in December 2006 as the NIH Reform Act of 2006 had contained language that would have clustered Institute and Center budgets, including that of the NEI.