**President’s Message**

$200 Million Increase for Vision Research Is 400-Fold Return on NAEVR/AEVR Investment

Between the economic stimulus and Fiscal Year (FY) 2009 appropriations, vision researchers will have access to at least an additional $200 million in funding from the National Eye Institute (NEI) and the Department of Defense (DOD). That is a 400-fold return on the vision community’s investment in NAEVR/AEVR, a remarkable return in today’s market. I commend NAEVR Executive Director James Jorkasky and his team of Advocacy Manager David Epstein and Legislative Counsel John Porter, as well as the NAEVR network members, who have advocated tirelessly for these funding increases with Congress and the new Obama Administration.

NAEVR had a constant presence and leadership position on Capitol Hill this first quarter of 2009 through vision advocacy and educational events.

While the economic downturn has been devastating for the private sector, that is, less funds for vision research from philanthropic organizations and industry, the federal government has made more funds available for vision research than ever.

Armed with data from Research!America about the $8.6 billion loss in National Institutes of Health (NIH) purchasing power over the past six funding cycles and November 2008 testimony by Acting NIH Director Raynard Kington, M.D., Ph.D., about the stimulative nature of NIH grants locally and nationwide, NAEVR was one of the first advocacy organizations to request $10 billion in NIH funding within economic stimulus legislation.

Of course, there were other propitious factors. Our Senate champions, especially Senate Labor, Health and Human Services, and Education (LHHS) Appropriations Subcommittee Ranking Member Arlen Specter (R-PA), supported by Chair Tom Harkin (D-IA), led the charge for this unprecedented request, and NAEVR committed to support these leaders who have done so much for NIH funding. Additionally, the incoming Obama Administration had signaled its support for increased science funding, and NAEVR urged the transition team to support the $10 billion NIH funding as a first step in the doubling of the NIH budget over the next ten years.

I was fortunate to have been in Washington, D.C. on February 11 to receive the Visionary Award from the Foundation Fighting Blindness at its annual Valentine’s Day Gala. Although I was humbled by FFB’s honor, I mention it solely to tell you about the energy I felt surrounding political change, especially that of policymakers toward funding science and research. Emcee Cokie Roberts emphasized the renewed importance of advocacy, observing that our community has a strong message about the value of vision research, especially its power to save and restore vision to ensure productive, independent, and quality lives.

I agree with Ms. Roberts. That is why I am so pleased that NAEVR has launched its efforts to celebrate the 40th anniversary of the NEI in 2009 and the Decade of Vision 2010-2020 initiative to maintain a sustained awareness of the value of federally funded vision research that benefits all Americans. As this edition goes to press, NAEVR is engaged with its Congressional champions to offer both House and Senate resolutions acknowledging the anniversary and designating 2010-2020 as The Decade of Vision. NAEVR will sustain that awareness through a June 11 Capitol Hill reception. NAEVR’s events will complement and expand upon those planned by the NEI, including its NIH campus event being held on April 3, the very day 40 years ago that the first meeting of the National Advisory Eye Council (NAEC) was held. NAEVR is ensuring that Congressional authorizers and appropriators with oversight of NIH are aware of these events.

I know these are very challenging economic times for our economy, and no one is immune from the downturn. That is why I want to offer a special thanks to all organizations which have contributed to NAEVR/AEVR in 2009. As you can see, the Alliances are strong and productive. Despite their small size relative to other organizations, NAEVR/AEVR are among the most effective in advocating and educating about the value of research. That fact is reinforced by the 400-fold return on investment!

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**Contributor Report**

Dr. Ryan offers comments at the February 11 Foundation Fighting Blindness Valentine’s Day Gala, where he received the Visionary Award. NAEVR/AEVR in 2009. As you can see, the Alliances are strong and productive.

Stephen J. Ryan, M.D.
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On March 17, the Subcommittee on Oversight and Investigations of the House Committee on Veterans’ Affairs held a hearing to discuss the status of implementation of the VCE and Military Eye Trauma Registry, which were authorized in the Fiscal Year (FY) 2008 National Defense Authorization Act (NDAA). The VCE/Injury Registry, a DOD program that coordinates with the VA, is a provision of the Military Eye Trauma Treatment Act sponsored by Cong. John Boozman (R-AR) that was included in the NDAA and supported by NAEVR.

From FY2006-2008, eye and vision research competed against 20 other areas of research for a $50 million pool of peer reviewed funds within the Peer Reviewed Vision Research Program (PRMRP) in the Congressionally Directed Medical Research Program (CDMRP). TATRC and CDMRP are ‘sister’ agencies within the U.S. Army Medical Research and Materiel Command (USMRMC).

NAEV R (Executive Director James Jorkasky and Advocacy Manager David Epstein) and ARVO (Executive Director Joanne Angle) served as Consumer Advocates at a March 12 meeting of the TATRC panel developing the program’s grant mechanisms and research topics, which are scheduled to be announced in late April. NAEVR and ARVO will also participate in the Programmatic Review portion of the awards process. The panel has representatives from TATRC, CDMRP, the DOD Vision Center of Excellence (VCE), the Department of Veterans Affairs (VA), and the Food and Drug Administration (FDA), as well as military ophthalmology and optometry consultants.

**House to DOD: “Fully Implement the Vision Center of Excellence”**

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In response to testimony by sight-impaired veterans about lack of coordination of care between the DOD and VA, VCE Director Colonel Donald Gagliano, M.D., stated that the VCE could serve as a trailblazer in coordinating a seamless transition, especially with respect to medical records, since the Injury Registry would track records longitudinally and bi-directionally. He added that the Registry will also drive appropriate research, especially that funded by the DOD’s Peer Reviewed Research-Vision program.

**DOD recently released a summary of its Vision Research Portfolio managed by TATRC and CDMRP. A PDF copy is available on NAEVR’s Web site.**

**Defense Vision Session at ARVO**

NAEV R will host a Monday, May 4, Defense-related Vision Research Briefing at the ARVO Annual Meeting, 7:30-8:30 am in Room 301 of the Fort Lauderdale Convention Center. Every academic institution should attend to hear about the FY2009 TATRC Program Announcement and other funding opportunities.

**CDMRP and DRMRP Announce Initial Awards**

In January, the CDMRP announced its FY2008 awards, which include 6 grants to vision researchers, valued at $10-12 million, in Advanced Technology/Therapeutic Development, Clinical Trials, and Translational Research. At press time, the Deployment Related Medical Research Program (DRMRP), a new mechanism created by the mid-year FY2008 Supplemental Appropriations Act, had just issued an announcement, also including vision awards. NAEVR has posted these awards on its Web site.
Legislative Scorecard Issues

$200 Million More for NEI From Economic Stimulus, FY2009 Appropriations

NEI has announced that it anticipates receiving $175 million over the next two years from the $10.4 billion NIH funding within the American Recovery and Reinvestment Act (ARRA, PL.111-5), signed by President Obama on February 17. In addition to those two-year stimulative dollars, the FY2009 Omnibus Appropriations Act (PL 111-8), signed by President Obama on March 11, increases NEI funding by $21.4 million to a level of $688.5 million (see funding chart). Although that 3.2 percent increase in annual appropriations is the largest since FY2004, it just barely matches the FY2008 biomedical inflation rate of 3.5 percent.

The $200 million more for NEI over its FY2008 funding level of $667 million from the recent legislative actions may represent a “floor” since vision researchers will have opportunities to seek funding from other NIH mechanisms (see summary chart). These include: the newly created “Challenge Grants”; NIH common fund (e.g., bridge funding, new investigator awards); extramural research/renovation/construction; and shared instrumentation.

NAEVR's Web Site Home Page Links to Dedicated Section on Economic Stimulus, Including Funding Notices

The $10.4 billion NIH Funding in the ARRA includes:

- $8.2 billion for research, $7.4 billion of which prorated to NIH Institutes, Centers (ICs) and the Common Fund, with $0.8 billion in Office of the NIH Director (includes $200 million for new “Challenge Grants” to address specific health challenges)
- $1.3 billion to the National Center for Research Resources (NCRR): $1 billion for extramural research repair/renovation/construction and $0.3 billion for acquisition of shared instrumentation and other capital research equipment
- $0.5 billion for NIH intramural buildings and facilities
- $0.4 billion transferred to NIH from the Agency for Healthcare Research and Quality (AHRQ) for comparative effectiveness research

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* FY2007 NEI excludes $8.5M for NEI programs due to direct appropriations to NIH Common Fund and $4.2M in NIH Director Bridge Awards
+ FY2008 figures include original appropriations sums of $29.28 NIH/667.1M NEI plus supplemental appropriations of $150M NIH/3.5M NEI. Final FY2008 NEI excludes $3M from Director’s Bridge Awards
++ Percent increase based on initial FY2008 appropriation (not including mid-year supplemental)

ARVO Researchers Support NIH/NEI Increase in January 23 Advocacy Day

As in past years, ARVO researchers were among the first on Capitol Hill in the new legislative session to advocate for increased NIH/NEI funding, as well as defense-related vision research within the DOD. In 35 visits, the 13 domestic and international researchers, hosted by ARVO and NAEVR staff, urged Members of the new 111th Congress to support NIH funding at a level of $10 billion in the economic stimulus, which echoed NAEVR’s request in a January 14, 2009, letter to President Obama’s transition team that NIH be funded at that substantial level. In that letter, NAEVR cited Research!America’s estimate that NIH has lost $8.6 billion in purchasing power over the past six funding cycles, due to biomedical inflation and the lack of a minimal three percent annual increase.

ARVO Advocacy Day Participants included (from left to right): Front Row: Debra Nickla, Ph.D. (New England College of Optometry); Suzanne Fleiszig, O.D., Ph.D. (University of California/Berkeley); Sally Atherton, Ph.D. (Medical College of Georgia); Muna Naash, Ph.D. (University of California/Berkeley); Sally Atherton, Ph.D. (University of California/Berkeley); Robert Clark, Ph.D. (University of Wisconsin); Paul Bernstein, M.D., Ph.D. (Miami University of Ohio); Michael Robinson, Ph.D. (Miami University of Ohio); Richard Harrad, FRCS (Bristol Eye Hospital, United Kingdom); Leonard Levin, M.D., Ph.D. (University of Wisconsin); Paul Bernstein, M.D., Ph.D. (Miami University of Ohio); Nancy Coletta, O.D., Ph.D. (New England College of Optometry); Joseph Carroll, Ph.D. (Medical College of Wisconsin); Not Shown: Dong Chen, M.D., Ph.D. (Schepens Eye Research Institute/Harvard Medical School); Ido Perlman, Ph.D. (Technion, Israel Institute of Technology); and ARVO staff members Joanne Angile (Executive Director), Bobbie Austin, Ph.D., and Lori Methia

NAEVR Urges At Least a Seven Percent Increase in FY2010 NIH/NEI Appropriations

Although commending Congress for the two-year stimulative dollars in the ARRA and the FY2009 inflationary increase, NAEVR is urging Congress to increase FY2010 NIH/NEI funding by at least seven percent, which reflects a modest increase to re-build the base plus biomedical inflation. This would result in NIH funding of $32.4 billion and NEI funding of $736 million.

Sen. Arlen Specter (R-PA) led efforts for $10B NIH increase. On March 24, Research!America recognized him with its Legacy Award.
On January 28, in the midst of stimulus debate, NAEVR and AEVR hosted a reception for Members of the 111th Congress and their staff. In his welcome comments, Cong. Pete Sessions (R-TX) announced NEI’s 40th anniversary in 2009. NAEVR/AEVR’s James Jorkasky added that the reception begins numerous events in 2009 to educate about the value of NEI-funded vision research. He also urged Hill offices to support a new NAEVR/AEVR initiative, Decade of Vision 2010-2020—a sustained effort to recognize federally funded vision research that benefits all Americans. NAEVR is working with its Capitol Hill champions to pass House and Senate resolutions that acknowledge NEI’s 40th anniversary and designate 2010-2020 as the Decade of Vision.

To recognize the second annual World Glaucoma Day (WGD) on March 12, AEVR sponsored a March 10 Capitol Hill briefing to educate Members of Congress and their staffs. In introducing the briefing, AEVR’s James Jorkasky read from a March 6 statement issued by NEI Director Paul Sieving, M.D., Ph.D., noting that NEI currently spends $65 million in support of 168 glaucoma studies, including the newly initiated NEI Glaucoma Human genetics collaboration, known as NEIGHBOR, through which seven U.S. research teams will lead genetic studies of the disease.

The featured speakers included Murray Fingeret, O.D., F.A.A.O., (Brooklyn/St. Albans Campus, Department of Veterans Administration New York Harbor Health Care System), who spoke about the incidence and burden of the disease, and Rohit Varma, M.D., M.P.H., (Doheny Eye Institute, University of Southern California), who spoke about research and treatments. Both speakers had participated in a March 13-14, 2008, joint NEI/Food and Drug Administration (FDA) Glaucoma Endpoints meeting at which researchers acknowledged that glaucoma is a complex, neurodegenerative disease in which detectable changes within the eye may not progress linearly or in concert with functional changes, that is, vision loss.

AEVR was joined by the American Glaucoma Society (AGS), ARVO, the Glaucoma Research Foundation (GRF), and The Glaucoma Foundation (TGF) in sponsoring the briefing, which was one of many hundreds of events being held around the globe.

Murray Fingeret, O.D., F.A.A.O. “Glaucoma prevalence in the U.S. is 2.2 million individuals and approaching 60 million individuals globally. However, anywhere from 50-75 percent of individuals with glaucoma are undiagnosed, as it often has no symptoms until vision is lost.”

Rohit Varma, M.D., M.P.H. “Researchers are studying the genetic basis of glaucoma and using genes to determine a potential response to medical treatment, that is, prior to treating, knowing how a drug is going to work.”

The Glaucoma Foundation’s Scott Chris tensen announces a glaucoma screening event conducted by a dozen eye specialists from The New York Eye and Ear Infirmary to be held on March 11 at the United Nations in New York City

Keagan Lenihan from the office of Cong. Sessions and Brette McClellan (Alcon Laboratories, Inc.)

NAEVR Advocacy Manager David Epstein with Janel George from the office of Cong. Donna Edwards (D-MD)

Left to right: NAEVR/AEVR’s James Jorkasky with Cong. Howard Coble (R-NC) and Cong. Pete Sessions (R-TX).

Left to right: The featured speakers with Cong. John Boozman (R-AR)
Imagine trying to live with the challenges of combined deafness and blindness and, at the same time, being unseen and unheard by society. That’s the unfortunate irony for the 45,000 Americans with Usher syndrome, a devastating inherited disease that robs people of their vision and hearing.

On February 5, AEVR and the Foundation Fighting Blindness (FFB) hosted a Capitol Hill briefing to make legislators aware of Usher syndrome and to support its increased research funding at NIH. The three NIH institutes currently funding research are the NEI, the National Institute on Deafness and Other Communications Disorders (NIDCD), and the National Institute of Child Health and Human Development (NICHD). Much of the research underway not only impacts people with Usher syndrome, it is providing important information about how all people see and hear.

Featured speaker William Kimberling, Ph.D., one of the world’s leading Usher syndrome authorities who conducts research at Boys Town National Research Hospital in Omaha, Nebraska, and at the University of Iowa in Iowa City, explained that the combined impact of hearing and vision loss is many times greater than deafness or blindness alone. “Deafness and blindness together is not like 1+1 = 2. It’s like 1+1 = 10,” he said, adding that, “Usher syndrome is a vicious disease.” His goal, simply stated, is to add at least 20 more years of vision for individuals who are often blind by age 20, just when they are starting to live independent lives.

Usher syndrome is caused by a genetic variation (a mutation) in the cells of both the retina and the inner ear. Genes lead to the production of proteins, and if a defective gene leads to a single missing or incorrect protein, it can mean serious trouble. Dr. Kimberling explained that Usher proteins in the retina work together like a crane to deliver important chemicals from one end of a cell to the other. If one protein isn’t doing its job, it’s like losing the motor or the hook or the cable, and ultimately, then the crane doesn’t work, and the health of the retina is severely affected. Dr. Kimberling added that much of what is known about Usher syndrome is relatively new information. “Up until about the year 2000, we had no idea that such a mechanism [the crane-like structure] existed.” So far, variations in nine genes have been linked to Usher syndrome, and researchers know there are more to be identified.

One immediate goal of Dr. Kimberling’s research is to provide inexpensive and accessible genetic screening for young children who are born deaf or with severe hearing loss to determine which of them is affected by Usher syndrome. He estimated that as many as 15 percent of these hearing impaired children will eventually lose their vision. However, if children with Usher syndrome can be identified early on, through genetic and vision testing, then measures can be taken right away to preserve their vision as much as possible. The progress of vision loss could potentially be slowed by the administration of neuroprotective treatments, which are in clinical studies right now. Also, nutritional supplementation with fish oil and vitamin A appears to slow vision loss in some individuals. Even wearing sunglasses in bright outdoor light might give a person two or three years of additional useful vision.

Not only does vision preservation provide these individuals with a better quality of life, it is likely to give them the opportunity down the road to benefit from an emerging curative treatment such as gene therapy, which Dr. Kimberling calls “the gold standard” for treating Usher syndrome. Additionally, he noted, by keeping individuals independent and productive, we can save much of the $2 billion that he estimates that Usher syndrome costs our economy annually in health care and other supportive services.

Dr. Kimberling emphasized that Usher syndrome research is greatly underfunded and the condition is greatly overlooked. “Few people have heard of the disease, yet it is more common than amyotrophic lateral sclerosis (ALS, or Lou Gehrig’s disease) or Huntington’s disease.”
NAEVR Engaged in Numerous Network Events Throughout the Country
Lions Clubs International Honors President Carter

On January 27, former President Jimmy Carter dedicated the “Gift of Life” statue at Lions Clubs International headquarters in Oak Brook, Illinois. The statue symbolizes Lions Clubs International Foundation’s (LCIF) collaborative efforts to prevent blindness and is a gift to Lions from The Carter Center. NAEVR was pleased to attend this event and speak at the accompanying Lions Sight Partners Forum.

President Carter and Al Brandel, Lions Clubs International President

Left: The “Gift of Life” statue, depicting a child leading a man blinded by river blindness

The NEI’s Rosemary Janiszewski, Associate Director for Communication, Health Education, and Public Liaison, spoke at the Sight Partners Forum about NEI’s research, education, and prevention activities

Photos courtesy Lions Club International

Vision Advocacy Partners Meet, Host March 3 Capitol Hill Reception

On December 4, Prevent Blindness America (PBA) called together a number of vision advocacy organizations, including NAEVR, to discuss ways to enhance the vision message. This umbrella group has continued to meet and coordinate activities as Vision Advocacy Partners. Many of these organizations, including NAEVR, co-sponsored a March 3 Congressional Vision Caucus Reception held in conjunction with PBA’s Eyes on Capitol Hill Advocacy Day.

At a December 17 dinner, John Werner, Ph.D., Professor of Ophthalmology and Vision Service and Professor of Neurobiology, Physiology and Behavior (University of California at Davis) received the 2008 Pisart Award in recognition of his contribution to the prevention, cure, or treatment of severe vision impairment or blindness. Dr. Werner (right) is joined by Lighthouse International President and CEO Tara Cortes, Ph.D., R.N. NAEVR’s James Jorkasky serves as a Pisart Jurist.

Photo Courtesy Dorothea Anne Lombardo

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Left to right: Cathy Cohen (American Academy of Ophthalmology), Kelly Hipp (American Optometric Association, AOA), Ed Greene (Vision Council of America), and Barry Barresi, O.D., Ph.D. (AOA) at the December meeting

Left to right: Andrea Densham (Prevent Blindness America) and legislative counsel Jeremy Scott (DrinkerBiddle Reath) speak with Congressional Vision Caucus co-chair Gene Green (D-TX) and his legislative assistant Abby Pinkele at the March 3 reception