



**NAEVR**  
National Alliance For  
Eye And Vision Research

*Serving as Friends of the National Eye Institute*

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## **National Alliance for Eye and Vision Research (NAEVR) Submission: NIH Listens.gov**

### **Background**

Serving as the “Friends of the National Eye Institute (NEI)” since 1993, NAEVR worked in 2009 with Congressional champions for passage of H. Res. 366 and S. Res. 209, which acknowledged the NEI’s 40<sup>th</sup> anniversary and designated 2010-2020 as *The Decade of Vision*, recognizing NEI’s future challenges and opportunities. We were also pleased that the book *History of the NEI 1968-2000* issued in the anniversary year, and provided our assistance to the authors—former NEI Director Dr. Carl Kupfer and former NEI Deputy Director Edward McManus—as they prepared this important record of accomplishments. We were also honored to join our advocacy colleagues on Capitol Hill in supporting President Obama’s nomination of Francis Collins, M.D., Ph.D., as NIH Director, as well as to co-sponsor the December 2, 2009, Capitol Hill welcome reception for him. On behalf of the community of support for eye and vision research, NAEVR is pleased to identify two specific concerns that relate to the future of the NIH overall, and NEI, specifically.

### **Concern 1: Robust NIH/NEI Funding**

The numerous 40<sup>th</sup> anniversary campus-based educational seminars that NEI has sponsored since April 2009 are testimony to its leadership in basic, translational, and clinical research, especially in ocular genetics. NEI’s Fiscal Year (FY) 2011 Congressional Justification also demonstrates that the Institute is responsive to the five priority areas for NIH, as identified by Dr. Collins. NEI also leads in collaboration with other NIH Institutes/Centers, other Department of Health and Human Services (DHHS) agencies (especially the Food and Drug Administration), and with private funding entities.

NAEVR, which sits on the Steering Committee of the Ad Hoc Group for Medical Research, has joined its advocacy colleagues in requesting FY2011 NIH funding at \$35 billion to fully leverage and maintain the current momentum of research. NAEVR was an early and ardent supporter of the American Recovery and Reinvestment Act (ARRA), and was among the first to share examples of ARRA-funded NEI breakthrough research with Congressional offices in October 2009 during an Advocacy Day of the Board of Trustees of the Association for Research in Vision and Ophthalmology (ARVO). We continued that momentum with a January 29, 2010, Advocacy Day—even prior to issuance of the President’s budget proposal—and included nine international researchers who spoke about the worldwide impact of NIH funding.

As Congress has essentially funded biomedical research at a level of \$35 billion in FY2009 and FY2010, NAEVR has expressed concern about the President’s budget in that it would only provide for an inflationary increase for NIH. We also expressed specific concern about the proposed 2.4 percent increase for the NEI, which is one of the lowest percent increases for an Institute. This is not the time for a less-than-inflationary increase for NEI for several reasons, including:

- The NEI budget has yet to double over the FY1998 level (FY2010 funding of \$707 million is less than the \$711 million budget-doubling goal).

- NEI lost 18 percent of its purchasing power in the six funding cycles in the FY2003-2008 timeframe. Another year with a less-than-inflationary increase adds to that net loss.
- NEI-funded research is resulting in treatments and therapies that can save vision and restore sight, which can reduce healthcare costs, maintain productivity, ensure independence, and enhance quality of life.
- Congress' designation of 2010-2020 as *The Decade of Vision* was predicated on the fact that NEI will face a daunting future challenge. Year 2010 begins a decade in which more than half of the 78 million Baby boomers will turn 65 years of age and be at greatest risk for developing aging eye disease.

NAEVR will urge Congress to not only improve on the President's FY2011 proposed funding level for NIH overall, but to also ensure that the NEI is appropriately funded.

### **Concern 2: Potential NIH Budget Clusters**

The Honorable John Porter has observed that no other "Friends" group fought as hard as NAEVR in the 2004-2006 timeframe to ensure that the NIH reauthorization legislation did not contain the proposed budget cluster proposal, and that the NEI budget line item was maintained. NAEVR continues to oppose the concept of budget clusters and not only attends the meetings of the NIH Scientific Management Review Board (SMRB) and its Working Groups, but also convenes meetings with the "Friends" of smaller Institutes to monitor these activities. In this 40<sup>th</sup> anniversary year of the NEI's creation, NAEVR wishes to reiterate its key points in opposition to budget clusters:

- Prior to 1968, vision research was conducted in the then-National Institute of Neurological Diseases and Blindness (NINDB), accounting for less than 20 percent of the Institute's budget.
- Since its creation in 1968 as a separate Institute, NEI has been a leader in basic, translational, and clinical research, conducting more than 65 clinical trials. It has also been a leader in trans-Institute NIH research, most notably its collaboration with the National Human Genome Research Institute (NHGRI) in elucidating the genetic basis of eye disease and vision impairment.
- In either a proposed "Brain" cluster or a "Mission-specific" cluster, larger Institutes could siphon away dollars from smaller Institutes.
- Although 50 percent of NEI-funded research relates to the "front of the eye," it would only account for 7 percent of a total "Brain" cluster budget. Future funding for this research could be jeopardized, including that into corneal diseases, cataracts, and refractive errors that affect millions of Americans and cost tens of billions of dollars, with devastating consequences for public health, productivity, and quality of life.
- If "front of the eye" research were not adequately funded, the vision community could permanently lose key investigators. Eye researchers and clinicians are uniquely qualified to understand and treat eye disease, since neurologists do not necessarily have an understanding of corneal disease or cataract.

NAEVR will maintain both its vigilance about and advocacy against actions that could jeopardize a dedicated budget line for the NEI.