



National Alliance for Eye and Vision Research

Comprised of a coalition of 55 professional, consumer and industry organisations involved in eye and vision research, NAEVR unites many people to achieve the best eye and vision care for all Americans.

James F Jorkasky, Executive Director, speaks to International Innovation about their progress

Could you explain the aim of the National Alliance for Eye and Vision Research (NAEVR) and what you seek to deliver?

Founded in 1997, NAEVR's mission is to achieve the best eye and vision care for all Americans through advocacy for federally funded vision research conducted primarily by the National Eye Institute (NEI) within the National Institutes of Health (NIH). As a 501c4 'social welfare' organisation, as defined by the United States (U.S.) Internal Revenue Service (IRS), NAEVR initially served as the privately funded 'Friends of the NEI' – educating Congress, the media, and patients about the value of NEI-funded vision research to seek greater funding. In this regard, NAEVR has proactively engaged in ensuring that the NEI maintains its dedicated budget line item in NIH appropriations, as there have been proposals in the past few years to cluster its budget into a larger 'Brain Institute' from which it was spun off in 1968. NAEVR's advocacy has also expanded to include research funded by the Department of Defense (DOD), the Department of Veterans Affairs (VA), and the Department of Energy (DOE).

To what extent does NAEVR collaborate with the NIH?

In the U.S., government agencies such as the NIH are precluded from advocating before Congress. As a result, many of the 27 Institutes and Centers (I/Cs) within the NIH have a complementary, privately funded 'Friends' organisation that delivers an advocacy message to Congress. As the 'Friends of NEI', NAEVR emphasises how NEI-funded breakthrough research is saving and restoring vision, thereby increasing productivity, ensuring independence, and improving quality of life. Obviously, with increased Congressional scrutiny of the federal budget, NAEVR stresses how treatments derived from NEI-funded research have the potential to reduce healthcare costs, especially to the Medicare and Medicaid programmes. Since NEI funds research at academic institutions across the U.S., NAEVR has also addressed the impact on local employment, especially the retention and recruitment of highly trained individuals who, if not funded, could be lost to other research areas or to institutions in other states or countries.

How does your work impact vision research?

NAEVR has had a tangible impact. In Fiscal Year (FY) 2009, federal funding for vision research exceeded US \$900 million for the first time, primarily driven by an additional \$230 million above the FY2008 funding baseline of \$670 million due to increased NEI appropriations, \$175 million of which came from the American Recovery and Reinvestment Act (ARRA) – more commonly called the economic stimulus, for which NAEVR was an early and strong advocate. The increase also included \$12 million in new funding from the DOD for research into penetrating eye injuries and visual dysfunction associated with Traumatic Brain Injury (TBI), which was made available to researchers through NAEVR's advocacy. In FY2010, vision researchers accessed an additional \$90 million over the FY2009 funding baseline of \$688 million, which included \$25 million in DOD funding. NAEVR has testified multiple times before the NIH's Scientific Management Review Board (SMRB) opposing NEI's inclusion in any proposed 'Brain Institute' – an initiative which has been abandoned for now – and has also urged NIH to ensure that any centralised authority for translational research does not stifle NEI's creativity which has made it a leader in such research, as recognised by NIH Director Francis Collins, MD, PhD.

What contribution to eye and vision research has the National Eye Institute made and how has it served to contain healthcare costs and improve the quality of life for millions of Americans?

In 2009, NAEVR recognised the 40th anniversary of the NEI with a series of Capitol Hill events noting its past accomplishments, which have been detailed in a publication entitled *History of the NEI: 1968-2000*, written by the first NEI Director Carl Kupfer, MD and former Deputy Director Edward McManus. Under the leadership of current Director Paul Sieving, MD, PhD, the NEI held a series of NIH campus-based scientific seminars that educated attendees on the breath of research and promising breakthroughs. One example is the series of Diabetic Retinopathy Clinical Research (DRCR) Networks that NEI has funded over the past 40 years. The initial network demonstrated that diet and laser treatment could

delay or prevent diabetic retinopathy, saving the U.S. about \$1.6 billion a year. Last year, the current DRCR Network's comparative effectiveness trial confirmed that laser treatment for diabetic macular edema, when combined with injections of an anti-angiogenic drug, is more effective than laser alone, the latter of which has been the standard of care for the past 25 years. NAEVR has numerous such examples, which it shares in Congressional office visits and in written and oral testimony.

What role does education play in NAEVR's strategy?

NAEVR was spun off of AEVR, the Alliance for Eye and Vision Research, which was founded in 1993 and as an IRS-defined 501c3 educational foundation has limits on advocacy activities. AEVR is the entity that conducts Capitol Hill briefings which educate Members of Congress and their staffs about the incidence of eye disease and the federal research being conducted to save and restore vision. AEVR conducts this education through its Decade of Vision 2010-2020 Initiative, which is a sustained effort to emphasise the impact of an aging population and concomitant increased risk of developing eye disease in this decade. The DOV was launched in 2009 through resolutions passed by both the U.S. House and Representatives and Senate that acknowledged the NEI's 40th anniversary and designated 2010-2020 as the decade of vision. In 2010, under the DOV banner, AEVR education included such topics as corneal wound healing on the battlefield, the artificial retina, low vision, the genetic basis of glaucoma, and the latest on age-related macular degeneration (AMD) research.

In what ways does the U.S. differ in its eye and vision research as well as its implementation when compared to its European counterparts?

Having spent time with my counterparts at the European Vision Institute (EVI) in June 2010 at the World Ophthalmology Congress in Berlin, I was impressed at how fortunate the U.S. is to have its federal vision research centralised through such entities as the NIH, DOD, and VA. In comparing advocacy strategies, I realised how difficult it is for my European colleagues, since they face a system that is far more complex due to potential funding opportunities at the European Union, country, and state level, as well as varied cultural attitudes about the relationship between the private and public sectors. In 2008, I was pleased to have written an International Advocacy Handbook for the Association for Research in Vision and Ophthalmology (ARVO), which is posted on its website, and to have worked with advocates from all over the world. Although advocacy approaches may differ, I think we all adhere to one universal message, which is that good vision is critical to an individual's quality of life, as well as to the productivity and economic vitality of a nation.

With a growing incidence of vision impairment and eye disease – especially that associated with an ageing and increasingly diverse population – how is NAEVR reacting to confront these challenges?

As noted above, the AEVR's DOV Initiative has emphasised the impact of the majority of the 78 million baby boomers reaching the age of 65 during this decade and the impact of the increased risk of aging eye disease. The DOV has also emphasised the disproportionate incidence of eye disease in fast growing African American and Hispanic populations. In advocacy, NAEVR has a compelling story to tell about NEI research in this regard, ranging from the development of anti-angiogenic drugs to stabilise the progression of the 'wet' form of AMD and to restore some vision, to the use of nutritional supplements to slow the progression to the advanced form of AMD. The NEI has also been a leader in the genetic basis of eye disease – in fact, one-quarter of all genes discovered to date are associated with eye disease – and NEI has networks of researchers studying the genetic basis of AMD and glaucoma.

How will you expand the qualitative and quantitative messages about the value and cost-effectiveness of the federal investment in eye and vision research?

Fortunately, NEI issues new research constantly. I describe these 'in plain English' on Capitol Hill, especially studies that have been funded by the FY2009/2010 appropriations and ARRA economic stimulus funding. I

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note how these address the five NIH priorities, as identified by Dr Collins: genetic basis of disease, translational research, comparative effectiveness research, global health, and re-invigorating the biomedical research community. In the DOD arena, NAEVR emphasises how research funded so far is being rapidly translated into low-cost, portable instruments that can be used on the battlefield to diagnose TBI and to seal corneal wounds. Obviously, the public and private sector's ability to develop quantitative data is often difficult and costly. However, NIH continues to develop strong messages about the value of research, and I am always pleased to quote Dr Collins or Dr Sieving in Congressional visits about the impact of vision research.

What plans for the future do you have?

Tough economic times often result in a call for greater efficiencies, and NIH's structure of 27 I/Cs is not beyond criticism. NAEVR's number one priority will remain maintaining the dedicated NEI budget line. Also, as NIH plans for a new centralised National Center for Advancing Translational Sciences (NCATS), which still must undergo Congressional review, NAEVR will monitor the potential impact on NEI's ability to enter into creative partnerships that have expanded upon its limited translational research funding and resulted in breakthroughs, such as the successful human gene therapy for Leber Congenital Amaurosis (LCA), a neurodegenerative disease which blinds young adults. Of course, NAEVR will continue to pursue every funding opportunity for vision researchers, who are very clever and collaborative and often proactively pursue funding from other NIH I/Cs, in addition to NEI. And as the conflicts continue in Iraq and Afghanistan, NAEVR will ensure that vision researchers have every opportunity to pursue the gaps in military eye trauma research identified by the DOD.

Would you like to discuss any other aspect of your work?

Yes. Obviously, the value of NIH/NEI is often seen through the eventual commercialisation of diagnostics and treatments. NAEVR is proud to have worked with ARVO in the past five years in organising with the NEI and the U.S. Food and Drug Administration (FDA) a series of joint NEI-FDA 'Endpoints Symposia' which have addressed how the results of NEI-funded research may affect regulatory processes used to review new ophthalmic drugs and devices. The Symposia have addressed such topics as AMD, glaucoma and diabetic retinopathy endpoints, as well as patient-reported outcomes. When NAEVR advocates, it acknowledges the NEI's leadership in collaborating with FDA, its 'sister' agency within the U.S. Department of Health and Human Services (DHHS), in getting products to patients in a more timely fashion.

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NAEVR
National Alliance For
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DECADE OF VISION
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