President’s Message

I am writing to you just after completing the testimony I will present on April 21 during the House LHHS Appropriations Subcommittee’s “Citizen Witness” hearing (see story inside). I am honored that NAEVR and ARVO (by President Dr. Gary Abrams) have been invited to present on behalf of the eye and vision research community and will be joined by other prestigious patient advocacy groups and coalition partners. I commend the work of our Legislative Counsel John Porter and our Executive Director Jim Jorkasky in ensuring that key Committee leaders are fully apprised of NAEVR’s message about the value of federally funded eye and vision research being conducted at the National Eye Institute (NEI).

NAEVR can make a strong case that eye and vision research should be a "top priority" among the many priorities Congress faces

In February, I joined John and Jim in strategy meetings. John advised that the NEI-derived eye disease incidence and economic cost data and the compelling examples of NEI’s basic and clinical research (such as the identification of a gene strongly associated with age-related macular degeneration) enable NAEVR to make a strong case for eye and vision research being a “top priority” among the many priorities Congress faces. Therefore, the NEI should be funded at $711 million in FY2006, or a 6 percent increase over FY2005. This is a leading statement in written testimony NAEVR submitted on March 9 to the House LHHS Subcommittee, and in my planned April 21 testimony. NAEVR will also make this point in written testimony submitted to the April 6 Senate LHHS Appropriations Subcommittee hearing.

Regarding that Subcommittee, I commend its chair Sen. Arlen Specter (R-PA) who once again demonstrated his support for medical research through an amendment to increase the FY2006 NIH budget by $1.5 billion over that proposed in the President’s Budget, to $30 billion. On March 17, both the amendment and the overall Senate Budget Resolution passed and now must be reconciled in conference with the House Budget Resolution, which maintains the President’s proposed FY2006 NIH increase of $200 million. NAEVR has strongly urged Congress to fund the NIH at $30 billion and $711 million, respectively.

We are still in the early stages of the budget and appropriations process, and much can still happen. We will continue to make our case, as shown by this report’s examples of outreach with Capitol Hill and coalition partners. I appreciate your commitment to NAEVR and ask that you enhance our efforts by contacting your Members of Congress and supporting NAEVR’s request for FY2006 NIH and NEI funding at $30 billion and $711 million, respectively.

—Stephen J. Ryan, MD
NAEVR/AEVR Boards President
e-mail: sryan@doheny.org
NATVR Works Closely with Contributors and Coalition Partners in Advocacy

BIO Investor Conference

On February 23-24, NAEVR participated in the Biotechnology Industry Organization's (BIO) Annual Investor Conference, providing informal comments about federal funding at a session entitled Biotech and Eye Disorders: Seeing Beyond the Obvious. In keynote comments, new BIO President James Greenwood, former Republican Congressman from Pennsylvania, announced BIO's expanded advocacy for governmental policies that result in timely product approval and coverage/payment decisions for new therapies resulting from medical research.

Research!America Annual Meeting

On March 15, NAEVR participated in the Research!America (R!A) annual meeting entitled Research: The Risks, the Rewards and the Returns which featured a panel including NIH Director Dr. Elias Zerhouni and CDC Director Dr. Julie Gerberding, along with research advocates. The panel acknowledged that, although the public strongly supports medical research, our community must do a better job of connecting future economic growth, educational progress and military defense effectiveness to a strong medical research base. John Porter, who serves as NAEVR Legislative Counsel, was elected R!A Board chair, succeeding former Florida Congressman Paul Rogers, who cautioned the audience in opening comments that, “Without research, there is no hope.”

AUPO Annual Meeting

On January 28, NAEVR conducted an advocacy breakfast at the annual meeting of the Association of University Professors of Ophthalmology (AUPO), one of the founding organizations of AEVR and NAEVR. In commenting on the responsiveness of AUPO members, NAEVR’s James Jorkasky noted that, “The Ophthalmology Department chairs have been among the first to contact Congress at pivotal times in the federal funding process. Many have developed close relationships with Members of Congress, so their voices greatly enhance our message about the value of research.”

"Without research, there is no hope"
—The Honorable Paul Rogers

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On March 9, NIH Director Dr. Elias Zerhouni appeared before the House Labor, Health and Human Services, and Education Appropriations Subcommittee, chaired by Cong. Ralph Regula (R-OH). His testimony offered compelling statistics—chronic diseases now account for 70 percent of all deaths and 75 percent of healthcare costs. Placing this challenge in context, he noted that the President’s FY2006 federal budget proposal of $28.6 billion for the NIH means that “it has $96 per each American to stem the rising burden of disease, as healthcare costs consume over $5,500 per-person, per-year.”

Within this context, Dr. Zerhouni identified how NIH is maximizing return on investment, primarily focusing on intra-Institute efforts that promote information-sharing and collaborative research, including the NIH Roadmap for Medical Research and the NIH Neuroscience Blueprint. He announced the creation of a new Office of Portfolio Analysis and Strategic Initiatives to better analyze and manage the NIH research portfolio.

On March 17, Dr. Zerhouni also testified before a House Energy and Commerce Health Subcommittee hearing entitled Setting the Path for Reauthorization: Management at the NIH. Subcommittee chair Cong. Nathan Deal (R-GA) noted that this was the tenth hearing on the NIH in the last two-plus years and prefaces NIH reauthorization activities in the 109th Congress, which full Committee chair Cong. Joe Barton (R-TX) echoed in announcing the introduction of bipartisan legislation in the coming months.

### NIH Budget Summary

**NIH**
- **FY2003 ACTUAL:** $27.2 B (+14.9%)
- **FY2004 ACTUAL:** $28 B (+3.1%)
- **FY2005 ACTUAL:** $28.4 B (+2%)
- **FY2006 PROPOSED:** $28.6 B (+0.5%)

**NEI**
- **FY2003 ACTUAL:** $632.3 M (+9.2%)
- **FY2004 ACTUAL:** $652.7 M (+3.3%)
- **FY2005 ACTUAL:** $669 M (+2.5%)
- **FY2006 PROPOSED:** $673.5 M (+0.7%)

*Source: NEI*
On March 9, NAEVR submitted written testimony requesting FY2006 NIH and NEI funding at $30 billion and $711 million, respectively—for each, an increase of 6 percent over FY2005. NAEVR supported the NEI request with the following main points:

• Eye and vision research responds to the nation’s top public health challenges of an aging population, chronic diseases, health disparities, emerging disease and bio-defense.

• The eye is a unique biological system in which to conduct genetic, neuroscience and cellular mechanism research.

• Vision impairment and eye disease is a major public health problem that disproportionately affects the aging and minority populations.

• The annual cost of vision impairment and blindness to the U.S. is $68 billion; adequately funding NEI is cost-effective, as it can delay, save and prevent expenditures to the Medicare and Medicaid programs.

• Past NEI-funded research has resulted in treatments and therapies to slow the progression of vision loss and to restore vision.

Full text of the testimony is available on www.eyeresearch.org
At this January 25 event, Sen. Jim Jeffords (I-VT) and researcher Dr. Neil Bressler (Wilmer Eye Institute/Johns Hopkins University) spoke about the impact of vision impairment and eye disease on patients.

In recounting his recent cataract surgery, Sen. Jeffords commented that, “Over the years my own vision was becoming impaired. Then, about two months ago, I underwent a procedure to have cataracts removed and it has literally changed my life. It has also made me aware of just how important vision, and vision research, is to my life.” He added that, “the Vision and Blindness fact sheet makes very clear the reward that we all reap from society’s investment in vision research and how it is improving the lives of people every day.”

Dr. Bressler, a retinal researcher, reported on his recently published study on patients’ perception of the value of vision (American Medical Association’s Archives of Ophthalmology, December 2004), sponsored by the NEI. Patients with the advanced stage of age-related macular degeneration (AMD, the leading cause of vision loss in older Americans) equated the ‘preference value’ for this condition to symptomatic HIV infection or chronic renal failure on home dialysis.

“This is an important finding,” said Bressler, “as an additional 200,000 Americans each year develop the advanced stage of AMD, and this number is expected to double in the next twenty years. We must have a strong, continuing federal commitment to all laboratory and clinical aspects of eye and vision research within the NEI to reduce the magnitude of blindness in this country and around the world.”


In a February 17 interview in Roll Call, Sen. Jeffords announced his intent to seek re-election in 2006 thanks to the eye and vision research community. “I feel good and healthy,” said the 70-year old, adding that, “I just got two new eyes; I feel better than I have in years” and noted that his recent cataract surgery “pumped up my spirit, so I think I’ll go another term.”
Our Community Shares the Value Message of Eye and Vision Research

On February 1, NAEVR participated in a Science Coalition briefing breakfast featuring Jennifer Miller, staff member of the House Appropriations Committee, chaired in the 109th Congress by Cong. Jerry Lewis (R-CA). She described the Committee’s reorganization and advised attendees that “if you want to hold your own in the next few challenging budget years, then continued communication with the Hill now is more important than ever.”

On February 9, NAEVR participated in the Foundation Fighting Blindness (FFB) For the Love of Sight Valentine’s Party, attended by key Members of the Administration and Congress, such as newly confirmed Health and Human Services Secretary Michael Levitt and Cong. Jerry Lewis (R-CA).

On March 10, Prevent Blindness America held a briefing in conjunction with the Congressional Vision Caucus entitled Saving Sight, Preserving Hope that described the National Vision Loss Prevention Program at the Centers for Disease Control and Prevention (CDC). Representatives of Prevent Blindness Ohio discussed their efforts within this program to identify many cases of undiagnosed and untreated eye diseases.
At the February 28 meeting, NEI welcomed four new members of the “class of 2008” to the National Advisory Eye Council (NAEC), including Dr. Gunilla Haegerstrom-Portnoy (University of California at Berkeley), Dr. Lenworth Johnson (University of Missouri at Columbia), Dr. Todd Margolis (F.I. Proctor Foundation/University of California at San Francisco) and Dr. Earl Smith (University of Houston).

Upcoming Events

**APRIL 14**
ARVO President Dr. Gary Abrams testifies before the House LHHS Appropriations Subcommittee (10:00 AM, House Rayburn 2358)

**APRIL 20**
AEVR Briefing: Glaucoma Detection and Treatment (Noon—1:15 PM, Senate Dirksen 226)

**APRIL 21**
NAEVR President Dr. Stephen Ryan testifies before the House LHHS Appropriations Subcommittee (10:00 AM, House Rayburn 2358)

**MAY 1**
NIH Director Dr. Elias Zerhouni speaks at the ARVO Annual Meeting (5:30 PM, Grand Floridian D, Ft. Lauderdale Convention Center)

**MAY 2**
NAEVR Legislative Breakfast at the ARVO Annual Meeting (7:30—9:00 AM, Room 207, Ft. Lauderdale Convention Center)

NAEVR at the National Advisory Eye Council Meeting

NAEVR is proud to acknowledge the following new contributors in 2005:

AMO (ADVANCED MEDICAL OPTICS)
EYETECH PHARMACEUTICALS, INC.
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