



NAEVR

National Alliance For
Eye And Vision Research

Serving as Friends of the National Eye Institute

1801 Rockville Pike
Suite 400, Attn: James Jorkasky
Rockville Maryland 20852
240-221-2905; jamesj@eyeresearch.org

**WRITTEN TESTIMONY IN SUPPORT OF INCREASED FISCAL YEAR (FY) 2013
FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH)
AND THE NATIONAL EYE INSTITUTE (NEI)
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED
AGENCIES SUBCOMMITTEE OF THE
U.S. SENATE COMMITTEE ON APPROPRIATIONS
March 29, 2012**

EXECUTIVE SUMMARY

NAEVR requests Fiscal Year (FY) 2013 NIH funding of at least \$32 billion, which reflects a \$1.38 billion, or 4.5 percent increase over FY2012, which consists of biomedical inflation of 2.8 percent plus modest growth, and is necessary since:

- After nearly a decade of budgets below biomedical inflation, NIH's inflation-adjusted funding is close to 20 percent lower than FY2003.
- Even before adjusting for inflation, enacted spending bills in recent years have cut the NIH budget. The looming sequestration mandated by the Budget Control Act threatens further cuts, estimated by the Congressional Budget Office (CBO) at eight percent in FY2013 alone.

NIH, our nation's biomedical research enterprise, is unique in that:

- Its basic and clinical research has helped to understand the basis of disease, thereby resulting in innovations in healthcare to save and improve lives.
- Its research serves an irreplaceable role that the private sector could not duplicate.
- It has been shown through several studies to be a major force in the economic health of communities across the nation. The latest United for Medical Research report estimates that NIH funding supported more than 432,000 jobs in 2011, directly or indirectly, and generated more than \$62.1 billion in economic activity.

NAEVR requests National Eye Institute (NEI) funding at \$730 million, commensurate with the overall NIH funding increase, especially since:

- Proposed FY2013 NEI funding of \$693 million reflects little more than one percent of the \$68 billion annual cost of eye disease/vision impairment in the US.
- The proposed \$693 million level is a \$14 million cut since FY2010, translating into 40 research project grants—any one of which could have cured blindness.
- In 2009, Congress spoke volumes in passing S. Res 209 and H. Res. 366, which designated 2010-2020 as *The Decade of Vision*, in which the majority of 78 million Baby Boomers will turn 65 years of age and face greatest risk of aging eye disease. A cut, level funding, or even an inflationary increase is not sufficient for NEI to meet the vision challenges presented by the "Silver Tsunami."

CONGRESS MUST IMPROVE UPON THE PRESIDENT'S FY2013 REQUEST, SINCE IT CUTS NEI FUNDING BY \$8.86 MILLION, OR 1.2 PERCENT BELOW FY2012, WHICH RESULTS IN FUNDING CLOSE TO THE BASE FY2009 LEVEL

Although the President's budget request level-funds NIH, it proposes to cut NEI by \$8.8 million. Although most of this cut reflects the NIH Office of AIDS Research pulling its funding from the NEI's Studies of Ocular Implications of AIDS (SOCA) clinical trials, which established the efficacy of combination antiviral drug therapy in treating cytomegalovirus (CMV) retinitis, the resulting total NEI funding of \$693 million reflects a level just slightly higher than that in FY2009, prior to the addition of American Recovery and Reinvestment Act (ARRA) funding. Although the NEI's Congressional Justification (CJ) notes that this funding level will still enable NEI to increase Research Project Grant (RPG) funding by \$3 million, it will still cut training programs and Research and Development contracts.

The FY2013 level also results in a net \$14 million loss of NEI funding since its highest level in FY2010, which translates into about 40 research grants—any one of which could hold the promise of curing a blinding eye disease. NEI is already facing enormous challenges in this *Decade of Vision 2010-2020*. Each day, from 2011 to 2029, 10,000 citizens will turn 65 and be at greatest risk for eye disease, the fast growing African American and Hispanic populations will experience a disproportionately higher incidence of eye disease, and the epidemic of obesity will significantly increase the incidence of diabetic retinopathy.

NAEVR requests NEI funding at \$730 million, reflecting biomedical inflation plus modest growth commensurate with that of NIH overall, since our nation's investment in vision health is an investment in overall health. NEI's breakthrough research is a cost-effective investment, since it is leading to treatments and therapies that can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life, especially since vision loss is associated with increased depression and accelerated mortality.

The very health of the vision research community is also at stake with a decrease in NEI funding. Not only will funding for new investigators be at risk, but also that of seasoned investigators, which threatens the continuity of research and the retention of trained staff, while making institutions more reliant on bridge and philanthropic funding. If an institution needs to let staff go, that usually means a highly-trained person is lost to another area of research or an institution in another state, or even another country.

FY2013 NIH FUNDING OF AT LEAST \$32 BILLION, NEI AT \$730 MILLION LETS NEI BUILD UPON ITS PAST RECORD OF BASIC AND TRANSLATIONAL RESEARCH

In late June 2010, NIH Director Francis Collins, M.D., Ph.D. recognized NEI's leadership in translational research at an NEI-sponsored *Translational Research and*

Vision Conference. Just two weeks earlier, Dr. Collins testified before the House Energy and Commerce Committee, stating that:

“Twenty years ago we could do little to prevent or treat AMD. Today, because of new treatments and procedures based on NIH/NEI research, 1.3 million Americans at risk for severe vision loss from AMD over the next five years can receive potentially sight-saving therapies.”

With FY2013 funding at \$730 million, NEI can build upon its past research, including:

Genetic Basis of Eye Disease: As NEI Director Paul Sieving, M.D., Ph.D. has stated, of the more than 2,000 genes identified to date, more than 500, or one-quarter, are associated with both common and rare eye diseases. By further understanding the genetic basis of eye disease, NEI can study underlying disease mechanisms and develop appropriate diagnostic and therapeutic applications for such blinding eye diseases as AMD, glaucoma, and retinitis pigmentosa (RP).

- NEI’s AMD Gene Consortium, which consolidates 15 international Genome Wide Association Studies (GWAS) representing over 8,000 patients, has validated 8 previously known gene variants and identified 19 new variants.
- NEI’s Glaucoma Human Genetics Collaboration (NEIGHBOR) has identified the first risk variant in a gene thought to play a role in the development of the optic nerve head, the degeneration of which leads to glaucoma and loss of peripheral vision, and then ultimately blindness.
- The NEI-led human gene therapy clinical trial for neurodegenerative eye disease Leber Congenital Amaurosis (LCA) has resulted to date in 15 patients being treated and experiencing visual improvement. NEI’s pioneering work, as well as subsequent refinement of gene therapy techniques, is enabling further research into ocular gene therapy through the launch of NEI-funded clinical trials for AMD, choroideremia, Stargardt disease, and Usher Syndrome. The latter three neurodegenerative diseases occur in early childhood and progressively destroy the retina, leading to vision loss and blindness and resulting in a lifetime of direct medical and indirect support costs. NEI is also funding pre-clinical safety trials for human gene therapy for RP, juvenile retinoschisis (“splitting” of the retina, resulting in vision loss), and achromatopsia (affecting color perception and visual acuity).

Diabetic Eye Disease: NEI’s Diabetic Retinopathy Clinical Research (DRCR) Network found that laser treatment for diabetic macular edema, when combined with anti-angiogenic drug treatment, is more effective than laser treatment alone and will revolutionize the standard of care in place the past 25 years. With the National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK) leading a new NIH strategic plan to combat diabetes, NEI’s research through its various diabetic eye disease networks over the past 40 years—in partnership with NIDDK—will be more important than ever.

BLINDNESS AND VISION LOSS IS A GROWING PUBLIC HEALTH PROBLEM THAT INDIVIDUALS FEAR AND WOULD TRADE YEARS OF LIFE TO AVOID

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. Although the NEI estimates that the current annual cost of vision impairment and eye disease to the US is \$68 billion, this number does not fully quantify the impact of indirect healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. NEI's proposed FY2013 funding of \$693 million reflects just a little more than one percent of this annual costs of eye disease. The continuum of vision loss presents a major public health problem, as well as a significant financial challenge to the public and private sectors.

Vision loss also presents a real fear to most citizens:

- In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer.
- NEI's *Survey of Public Knowledge, Attitudes, and Practices Related to Eye Health and Disease* reported that 71 percent of respondents indicated that a loss of their eyesight would rate as a "10" on a scale of 1 to 10, meaning that it would have the greatest impact on their day-to-day life.
- In patients with diabetes, going blind or experiencing other vision loss rank among the top four concerns about the disease. These patients are so concerned about vision loss diminishing their quality of life that those with nearly perfect vision (20/20 to 20/25) would be willing to trade 15 percent of their remaining life for "perfect vision," while those with moderate impairment (20/30 to 20/100) would be willing to trade 22 percent of their remaining life for perfect vision. Patients who are legally blind from diabetes (20/200 to 20/400) would be willing to trade 36 percent of their remaining life to regain perfect vision.

NAEVR URGES CONGRESS TO FUND NIH AND NEI AT FUNDING LEVELS OF AT LEAST \$32 BILLION AND \$730 MILLION, RESPECTIVELY, WHICH ENSURES THE MOMENTUM OF RESEARCH AND RETENTION OF TRAINED PERSONNEL

ABOUT NAEVR

The National Alliance for Eye and Vision Research (NAEVR), which serves as the "Friends of the NEI," is a 501(c)4 non-profit advocacy coalition comprised of 55 professional (ophthalmology and optometry), patient and consumer, and industry organizations involved in eye and vision research. Visit NAEVR's Web site at www.eyeresearch.org.