



NAEVR

National Alliance For
Eye And Vision Research

Serving as Friends of the National Eye Institute

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**Hearing on Fiscal Year (FY) 2014 Budget Priorities for Labor, Health and Human
Services, and Related Agencies Appropriations before the
Subcommittee on Labor, HHS, and Education and Related Agencies
March 13, 2013
10:00 am**

**Testimony by Hendrik P.N. Scholl, M.D., M.A.
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Baltimore, Maryland
On behalf of the National Alliance for Eye and Vision Research**

The National Alliance for Eye and Vision Research (NAEVR) requests Fiscal Year (FY) 2014 National Institutes of Health (NIH) funding at \$32 billion and National Eye Institute (NEI) funding at \$730 million. This funding represents the minimum investment necessary to make up for the twenty percent loss in purchasing power in the last decade due to flat funding and biomedical inflation, as well as the sequester's impact.

Good morning Chairman Kingston, Ranking Member DeLauro, and members of the Subcommittee, and thank you for the opportunity to appear today in support of appropriations for the National Institutes of Health (NIH) and the National Eye Institute (NEI). I am Hendrik Scholl, M.D., and I serve as The Dr. Frieda Derdeyn Bambas Professor of Ophthalmology at the Wilmer Eye Institute of the Johns Hopkins School of Medicine in Baltimore, Maryland.

I am representing the National Alliance for Eye and Vision Research (NAEVR), an Alliance of 55 member organizations representing professional societies in ophthalmology and optometry, patient and consumer groups, and industry. NAEVR serves as the "Friends of the National Eye Institute" and advocates for adequate funding for NEI's mission of saving and restoring vision.

I am here today to urge your support for a Fiscal Year (FY) 2014 NIH funding increase to a level of at least \$32 billion, as well as an increase in NEI funding to a level of \$730 million. This recommendation reflects the minimum investment necessary to make up for the twenty percent loss in purchasing power over the last decade due to flat funding and biomedical inflation, as well as the impact of the sequester, which cuts 5.1 percent or \$1.6 billion from NIH's \$30.6 billion budget.

I received my medical degree in Germany and did a fellowship in London, so I bring an international perspective to the need for adequately funding medical research. The NIH has long held a unique role in the world as the driver of biomedical research, the training ground for the next generation of scientists, a creator of jobs and source of economic development, and a leader in the competitive, innovation-based global marketplace. Without continued adequate investment, the United States will not only lose its leadership position, it will also fail to build upon the past investment in research to understand the basis of disease and develop treatments that save and improve lives. Vision research at the NEI has also been affected, with the sequester cutting \$36 million from its \$703 million budget. This could potentially result in about 90 new grants not getting funded—any one of which could hold the promise for saving or restoring vision.

The FY2013 cut and the potential for reduced, flat, or a minimal increase in FY2014 funding could not come at a worse time. During the decade 2010-2020, the majority of the 78 million “Baby Boomers” will turn age 65 and be at greatest risk of aging eye disease. More than 38 million Americans age 40 and older already experience blindness, low vision, or an age-related eye disease such as age-related

macular degeneration (AMD), glaucoma, diabetic retinopathy, or cataracts. This number is expected to grow to more than 50 million Americans by the year 2020.

In 2009, both the House and Senate spoke volumes in passing resolutions that designated 2010-2020 as *The Decade of Vision* in anticipation of the extraordinary vision challenges presented by this “Silver Tsunami.” We are asking Congress to ensure that the NEI has the funding necessary to address these challenges.

I am a clinician-scientist who focuses on diseases of the retina, which is the light-sensitive back of the eye necessary for vision. My specialty is retinal degenerations, especially AMD, which is the leading cause of vision loss in individuals over 60 years old and the leading cause of vision loss in the industrialized world due to the aging of the population. Each year, 200,000 Americans develop advanced AMD, resulting in a loss of central vision and an inability to read, drive, and conduct activities of daily living.

Fifteen years ago, there was not a lot new in AMD research, but now it is one of the hottest areas. In 2010, NIH Director Dr. Francis 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 in part on NIH research, 1.3 million Americans at risk for severe vision loss over the next five years can receive potentially sight-saving therapies.”

The NEI has been a leader in determining the genetic basis of eye disease. In fact, one-quarter of all genes discovered to-date have been associated with both common and rare eye diseases. The NEI has especially been a leader in the genetic basis of AMD. NEI’s AMD Gene Consortium, a network of international investigators, has just discovered seven new regions of the human genome—called loci—that are associated with increased risk of AMD. They also confirmed 12 loci already identified in

previous studies. These loci implicate a variety of biological functions, including regulation of the immune system, maintenance of cellular structure, growth and permeability of blood vessels, lipid metabolism, and atherosclerosis. By understanding the genetic basis of the disease and the underlying disease mechanism, NEI can develop appropriate diagnostic and therapeutic applications.

The NEI is also supporting research that restores vision. In February, the Food and Drug Administration (FDA) approved an implanted retinal prosthesis to treat adult patients with advanced Retinitis Pigmentosa (RP), a rare genetic condition that damages the retina and leads to blindness. A small video camera mounted on a pair of glasses sends images to a video processing unit that converts them to electronic data that is wirelessly transmitted to an array of electrodes implanted onto the retina. The device is enabling those who are otherwise completely blind to identify doors, crosswalks, and even utensils on a table.

Although this “Bionic Eye” may have been a fantasy just a few short years ago, the NEI has always envisioned the future. In late February, it hosted an *Audacious Goals* Development meeting where 200 representatives from every sector of the vision community, as well as government scientists and regulators from various disciplines and even entrepreneurs, met to shape NEI’s research agenda well beyond its five-year strategic plan. The discussion topics were built around the ten winning submissions from a pool of nearly 500 entries selected through NEI’s *Audacious Goals in Vision Research and Blindness Rehabilitation Challenge*, a worldwide competition for compelling one-page ideas to advance vision science. These ideas included restoring light sensitivity to the blind, precision correction of defective genes, and growing healthy

tissue from stem cells for ocular tissue transplants. But making these goals a reality will take adequate funding.

In closing, I 'd like to note that, in public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. Patients with moderate to severe vision loss would trade years of remaining life for perfect vision. For example, patients who are legally blind due to diabetes would be willing to trade up to 36 percent of their remaining life to regain perfect vision.

In summary, NAEVR requests FY2014 NEI funding at \$730 million 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.

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.eyerresearch.org.