

**Testimony of
The National Alliance for Eye and Vision Research (NAEVR)
to the
House Appropriations Subcommittee on Labor, HHS, Education
May 7, 2003**

The National Alliance for Eye and Vision Research (NAEVR) is pleased to have the opportunity to submit its views to the Committee. NAEVR is a nonprofit advocacy coalition of 42 organizations dedicated to expanding our national capacity to address eye and vision research opportunities and to ensure the best eye health for all Americans. The NAEVR organizations represent the spectrum of vision research and eye health interests, including researchers, providers, consumer advocates and industry.

My name is Evelyn Echols. I am one of the first successful women entrepreneurs and the first woman inducted into Rotary International. At age 88, I still lead a busy life: I serve on 10 civic, corporate, and charity boards, I lecture on entrepreneurship at major universities throughout the United States, and shortly, I'll begin a nationwide tour introducing my new book, "Saying Yes to Life". All this despite the fact that I have advanced macular degeneration in both eyes. Actually, there are some definite positives to this problem. For example, I can't see her friends' wrinkles, so they'll always be young to me.

I would like to begin by thanking the Committee for your continuing commitment to biomedical research supported by the National Institutes of Health (NIH) and the National Eye Institute (NEI). Congress has been tremendously supportive of pushing the frontiers of medical research through support of the NIH and the NEI. We know that you have many difficult decisions with regard to funding priorities in your Appropriations Bill and we appreciate the strong support that you have provided NIH. With this funding, NEI supported researchers have developed several promising experimental treatments with the potential to halt vision loss and restore sight for millions of Americans. We are now at a turning point. Clinical trials testing a number of new treatments are within our grasp. To advance these promising treatments to clinical trials requires a strong, sustained financial commitment from the federal government.

FY 2004 Funding Request:

While we commend the leadership of your committee and the President in achieving a doubling of the NIH budget over the past five

years, we are disappointed in President Bush and the House leadership for proposing only a 2% funding increase for NIH. We believe that such a small increase would harm the momentum built up over the past five years and ultimately neutralize all the gains that we have made. Because of the progress we have seen, the opportunities for substantial return on investment in medical research have never been greater. We urge the Committee to provide at least a \$3 billion increase for NIH, resulting in a total NIH budget of \$30 billion in Fiscal Year 2004.

Within the context of the NIH budget, the National Alliance for Eye and Vision Research requests your support for an NEI budget of \$711 million in Fiscal Year 2004. This funding level represents the professional judgment of the vision research community as the level necessary to advance important discoveries resulting from previous investments and to pursue new scientific opportunities. The National Alliance for Eye and Vision Research has framed the following set of priorities which, if adequately supported, will move the field of vision research significantly forward and provide translational benefits to additional NIH priorities.

Neurodegenerative Eye Diseases. Significant advances have been made in research on neurodegeneration across a range of eye diseases, including retinitis pigmentosa, ocular albinism, macular degeneration, and glaucoma. For example, scientists have linked a gene on the X chromosome that is normally associated with a form of retinitis pigmentosa that causes a blinding loss of rod photoreceptor cells with a unique type of cone photoreceptor cell degeneration of the macula. These investigations offer fresh insights on these diseases and suggest new intervention points for prevention and therapy. In light of these exciting developments, additional resources are needed to increase support for research on neurodegenerative eye diseases. Support for extramural research should be expanded, including support for genomic and proteomic resources and for collaborative multidisciplinary research.

Genetics and Gene Therapy Approaches to Neurodegeneration. Ongoing genetic studies are revealing the normal function of genes and how those functions are impaired when genes mutate which in turn will provide essential insight into many types of vision dysfunction. Gene therapy holds great potential as a therapeutic strategy to halt the progression of many forms of blinding eye diseases, including macular degeneration, retinitis pigmentosa, and glaucoma. Gene therapy has

already proven to be successful in preventing vision loss and restoring sight in canine and rodent models with forms of retinitis pigmentosa, a group of inherited incurable forms of blindness. Increased support for the NEI will expedite additional study of gene therapy applications to establish the safety of these potential cures in order to move to clinical trials.

Bioengineering and Advanced Instrumentation. NEI is pursuing the development of advanced assistive devices for the visually impaired, adaptive optics and other imaging techniques to improve non-invasive examination of ocular tissues for both research and disease diagnosis, instruments to analyze the biomechanics of the eye, and instruments to analyze visual performance. Additional study is needed in tissue bioengineering related to artificial cornea and adult stem cell research to replace or regenerate corneal tissue damaged by injury or disease, as well as into other applications of innovative technologies that will enhance or restore vision.

Health Disparities. Research in this area will enhance our understanding of glaucoma, diabetic retinopathy, and myopia incorporating studies of co-morbidity, natural history, and genetics with special emphasis on populations at increased risk. For example, rates of blindness from glaucoma are six times higher in African-Americans than in Caucasians, however age-related macular degeneration is rare for African-Americans as compared to Caucasians. Mexican-Americans have a high rate of diabetes that can lead to the development of the major complications of diabetes, including diabetic retinopathy. NEI-supported researchers have found that 20 percent of a population-based sample of Mexican-Americans living in Tucson and Nogales, Arizona had diabetes. Many of the participants did not realize they had diabetes and almost a quarter of these already had moderate diabetic retinopathy.

Low Vision. A related area of concern is low vision, or vision impairment which is not correctable by glasses or contact lenses. Currently, there are more than one million Americans today in the U.S. who are legally blind and 2.3 million are visually impaired. More than 50,000 Americans lose their sight each year and nearly half of these individuals go blind needlessly. Approximately 30 million Americans suffer from age-related threats to sight, namely macular degeneration, glaucoma, cataracts and diabetic retinopathy. These conditions are expected to nearly double by the year 2030 as the baby-boomers retire. By the year 2030, more than 66 million Americans will be at risk of

developing a common eye disease. Even more serious are the eye diseases which cause visual impairment in children. These include retinopathy of prematurity, cortical visual impairment, and coloboma. Low vision in children often affects their development and results in the need for special education, vocational training, and social services throughout their lives.

Glaucoma. Recent studies have substantially advanced our knowledge of glaucoma. The Ocular Hypertension Treatment Study demonstrated that eye drops used to treat elevated pressure inside the eye can be effective in delaying the onset of glaucoma in patients at higher risk for development of the disease. The Early Manifest Glaucoma Trial showed that immediate therapy to lower elevated intraocular pressure in patients with newly detected open angle glaucoma delayed and reduced the frequency of progression. Both studies underscore the need for early treatment of high intraocular pressure to slow or prevent glaucoma damage and subsequent vision loss until the means to prevent the disease itself can be discovered.

Diabetic Eye Disease. Diabetic retinopathy is the leading cause of new cases of blindness in this country. Diabetic macular edema, secondary to diabetic retinopathy, is a major cause of vision loss due to the leakage of fluids and other materials from damaged blood vessels. The NEI is implementing the recommendations of the Diabetes Research Working Group related to diabetic eye disease and has initiated plans to develop and evaluate more rapidly new treatments for macular edema through a new multicenter clinical trials network.

NAEVR also supports the National Eye Health Education Program (NEHEP). This public education partnership is coordinated by the NEI in partnership with over 60 national organizations that conduct eye health education programs. NEI has developed a program directed at low vision in order to increase public awareness about visual impairment and to encourage early detection and treatment. The Low Vision Traveling Exhibit launched early last year, also known as the "Eye Site", is being displayed in shopping malls around the country during the next five years. The program provides information about low vision services and the devices which are currently available to assist those with visual impairments. This effort is directed at those suffering from visual impairments and also to medical professionals, eye care specialists, managed care organizations, and family members. NAEVR urges the Committee to express their support for the continuation of this program and other important eye health public education initiatives.

If we do not make significant investments in vision research, we will have both a health care and economic crisis in this country, given our nation's demographics. With increased support for the NEI, we can make treatments for many vision diseases and disorders happen within our lifetime.

Conclusion: Mr. Chairman, the National Alliance for Eye and Vision Research supports an increased research focus on eye and vision disorders. The benefits of this research will improve the quality of life for all Americans by allowing individuals to remain independent and lead productive, fulfilling lives. We urge the Committee to provide a total NEI budget of \$711 million in Fiscal Year 2004. We also strongly support a total appropriation of \$30 billion for the NIH in Fiscal Year 2004. In this time of great medical discovery, we must do our best to find ways to prevent and treat eye and vision disorders and provide quality eye care services and devices for those who are already suffering from visual impairment.

Thank you for allowing the National Alliance for Eye and Vision Research to present its views.