



NAEVR

National Alliance For
Eye And Vision Research

Serving as Friends of the National Eye Institute

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Labor, Health, and Human Services, Education and Related Agencies Subcommittee

Senate Committee on Appropriations

Increased Funding for the National Institutes of Health (NIH) and National Eye Institute (NEI)

Serving as “Friends of the National Eye Institute,” the National Alliance for Eye and Vision Research (NAEVR) is a 501(c)4 non-profit advocacy coalition comprised of over 55 organizations, research institutions, and companies involved in and supportive of eye and vision research. NAEVR is grateful to Congress, especially the House and Senate Labor, Health, and Human Services (LHHS) Appropriations Subcommittees, for the strong bipartisan support for NIH funding increases over the past eight years. The \$15.16 billion increase during that timeframe has helped the agency, and researchers, regain lost ground after a decade of effectively flat budgets.

Support NIH Base Funding of at least \$50.9 Billion

The past increased investments in NIH have continued to improve our understanding of fundamental life and health sciences, advance research across conditions, and prepare the nation to combat existing and future health threats, including COVID-19. To maintain and build on this momentum, NAEVR strongly supports a funding level of at least \$50.9 billion for the NIH’s base program level, a \$3.44 billion increase over the comparable FY23 enacted level, with an emphasis that any additional funds for the Advanced Research Projects Agency for Health (ARPA-H) supplement, rather than supplant, the core investment in NIH Institutes. This increase would help keep NIH’s base budget ahead of the biomedical research and development price index (BRDPI) and provide for inflation plus growth to support promising science across the Institutes and Centers.

NAEVR continues to support ARPA-H funding and supports any funding above the \$1.5 billion allocated in FY23 to be supplemental to the NIH base budget as referenced above. NAEVR is further interested in identifying and supporting ways that vision researchers can engage in advanced research projects through ARPA-H given how vital vision researchers have proven to be across advancements in multiple conditions.

Support NEI Funding of \$975 Million

NAEVR also urges Congress to fund the National Eye Institute at \$975 million, a \$78.45 million increase over the comparable FY23 enacted level. Vision researchers continue to perform extremely well in cross-NIH initiatives because of how central the eye is to vision and provide one of the best windows into the brain and brain function. While funding for NEI has increased along with other NIH institutes over the past eight years, the FY23 funding level continues to remain below 2012 inflation-adjusted dollars.

NEI will play an even greater role in research that can stem the tide of the looming vision epidemic in the United States. The Centers for Disease Control (CDC) estimates three-in-five Americans over 40 have eye and vision problems (90 million). By 2050, CDC estimates a 72% increase in diabetic retinopathy, an 87% increase in cataracts, a 100% increase in glaucoma, a 100% increase in macular degeneration, and a 150% increase in vision impairment and blindness. Americans are facing an increasing burden of vision impairment and eye disease due to an aging population, the disproportionate impact risk and incidence of eye disease in fast-growing minority populations, and comorbidities impacting vision from numerous chronic conditions such as diabetes. With an ever-increasing reliance on electronic communication and screen time for children and adults, increased rates of myopia, dry eye, and eye strain are all expected to impact future generations.

Maintaining the momentum of vision research and increasing investment in vision research is vital to vision health and Americans' independence and quality of life. In a 2014 Research!America and Alliance for Vision Research (AEVR) survey of over 2,000 adults, vision loss was rated as potentially having the greatest effect on their day-to-day life, greater than the loss of limb, memory, hearing, and speech. Maintaining the momentum of vision research is vital to vision health, as well as to overall health and quality of life. Since the United States is the world leader in vision research and training the next generation of vision scientists, the health of the global vision research community is also at stake.

NEI-Funded Research Saves Sight and Restores Vision

The past federal investment in vision research has led to major advances in the prevention of vision loss as well as the restoration of vision.

Audacious Goals Initiative: The NEI has been at the forefront of regenerative medicine with its Audacious Goals Initiative (AGI), which launched in 2013 with the goal of restoring vision. Engaging a broad constituency of scientists from the vision community and numerous other disciplines, the AGI currently funds major research consortia that are developing innovative ways to image the visual system. Researchers can now look at individual nerve cells in the eyes of patients in an examination room and learn directly whether new treatments are successful. Another consortium is identifying biological factors that allow neurons to regenerate in the retina. And the AGI is gathering considerable momentum with current proposals to develop disease models that may result in clinical trials for therapies within the next decade.

Retinal Diseases: The NEI has been at the forefront of research into retinal diseases. NEI-funded researchers helped show that a protein called Vascular Endothelial Growth Factor (VEGF) stimulates abnormal blood vessel growth that occurs in the advanced stages of the “wet” form of Age-related Macular Degeneration (AMD) and Diabetic Retinopathy. Food and Drug Administration (FDA)-approved anti-VEGF drug therapies that slow the development of blood vessels in the eye delay vision loss and may improve vision for patients. The NEI has funded comparison trials of anti-VEGF drugs to provide eye care professionals and patients with the information they need to choose the best treatment options.

With respect to the “dry” form of AMD, known as geographic atrophy and the leading cause of vision loss among individuals aged 65 and older, in late 2019 NEI began a first-in-human clinical trial that tests a stem cell-based therapy from induced pluripotent stem cells (iPSC) to treat geographic atrophy. This trial converts a patient’s own blood cells to iPSC cells which are then programmed to become retinal pigment epithelial (RPE) cells, which nurture the photoreceptors necessary for vision and which die in geographic atrophy. Bolstering remaining photoreceptors, the therapy replaces dying RPE with iPSC-derived RPE.

Genetics/Genomics: The NEI has been at the forefront of genetics/genomics and gene therapy approaches to various vision disorders—both common and rare. The causes of AMD and glaucoma remain elusive—although most cases are not inherited, genetics does play a role. While NEI-funded researchers have identified many genetic risk factors for AMD and glaucoma, further study of these genes is helping to elucidate the biology of these disease and holds promise for improved therapies.

NEI-funded research has also made discoveries of dozens of rare eye disease genes possible, including the discovery of RPE65, which causes congenital blindness called Leber congenital amaurosis (LCA). As of late 2017, NEI’s initial efforts led to a commercialized, Food and Drug Administration (FDA)-approved gene therapy for this condition. These gene-based discoveries are forming the basis of new therapies that treat the disease and potentially prevent it entirely.

Front-of-Eye Research: The NEI has launched an Anterior Segment Initiative (ASI) to capitalize on research opportunities at the front of the eye. The ASI is addressing clinically significant, quality-of-life problems such as ocular pain and Dry Eye Disease (DED), especially in terms of pain and discomfort sensations, as well as disruptions in the tearing process. Using multi-disciplinary approaches, the ASI plans to elucidate relevant anterior segment innervation pathways that contribute to normal or abnormal functioning of the neural circuits related to the ocular surface.

Economic Burden of Eye and Vision Conditions

Vision disorders represent the fifth-highest direct medical cost in the United States. In a 2014 Prevent Blindness study, it was reported that vision disorders will cost an estimated \$182.5 billion in 2023 – only less than heart disease, cancers, emotional disorders, and pulmonary conditions. Left unaddressed, and with the looming vision epidemic, this is projected to grow to an inflation-adjusted \$717 billion by 2050. The U.S. is spending over \$545 per American on the

treatment of vision disorders every year while only spending \$2.66 per American on research that can improve outcomes. [<http://costofvision.preventblindness.org/>]

NEI's breakthrough research is a cost-effective investment that has led to treatments and therapies that may delay, save, and prevent health expenditures. It can also increase productivity, help individuals maintain their independence, and improve their quality of life as vision loss is associated with increased depression and accelerated mortality.

Summary

NAEVR supports the efforts of Congress to provide an eighth consecutive year of increases in the base funding for NIH. This funding is vital to building on the momentum of existing research and NAEVR is confident a funding level of at least \$50.9 billion will provide the necessary increase in FY24 to continue this growth. Inflation plus growth investment for the National Institutes of Health (NIH) and specifically the National Eye Institute (NEI), is vital to ensure we do not fall short of the Institute's ability to respond to the research needs of today to improve the outcomes of patients in the future.

NAEVR supports the NEI and believes that a funding level of \$975 million would reflect the urgent need to address eye and vision research in the United States. This funding would allow NEI to support researchers to identify new treatments, therapies, and interventions and address the future crisis in vision care as Americans age and more Americans rely on increased screen time to remain productive.

NAEVR thanks the LHHS Appropriations Subcommittee for the opportunity to submit this written testimony, especially as it continues to grapple with the multitude of short and long-term funding challenges.

For more information, or if the Subcommittee has additional questions, please contact Dan Ignaszewski, Executive Director of NAEVR at 240-221-2905 or Dan@eyerresearch.org. Additional information can also be found on NAEVR's website at www.eyerresearch.org. Thank you again for your time and consideration,

Sincerely,

A handwritten signature in black ink that reads "Dan Ignaszewski". The signature is written in a cursive style with a large, stylized "D" and "I".

Dan Ignaszewski

Executive Director
National Alliance for Eye and Vision Research