NAEVR
National Alliance For
Eye And Vision Research
Serving as Friends of the National Eye Institute

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TESTIMONY SUPPORTING INCREASED FISCAL YEAR 2020 FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND NATIONAL EYE INSTITUTE (NEI)

LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES SUBCOMMITTEE OF THE HOUSE COMMITTEE ON APPROPRIATIONS
April 8, 2019

EXECUTIVE SUMMARY

NAEVR, on behalf of the vision community, thanks Congress, especially the House and Senate Appropriations Subcommittees on Labor, Health and Human Services, and Education (LHHS), for the strong bipartisan support for the National Institutes of Health (NIH) funding increases from FY2016 through FY2019. The $9 billion increase has helped the agency regain some of the ground lost after years of effectively flat budgets. In Fiscal Year (FY) 2020, NAEVR urges Congress to appropriate at least $41.6 billion for NIH, a $2.5 billion or 6.4 percent increase over the FY2019 program level. This increase would allow for meaningful growth above inflation in the base budget to support promising science across all Institutes and Centers (ICs), as well as to ensure that funding from the Innovation Account established through the *21st Century Cures Act* would supplement NIH's base budget, as intended, through dedicated funding for specific programs.

NAEVR also urges Congress to appropriate at least $850 million for the NEI, a $53 million or 6.4 percent increase over enacted FY2019. The NEI, which in 2018 celebrated the 50th anniversary of its creation by Congress in 1968, is the world leader in sight-saving and vision-restoring research. Congress must ensure robust NEI funding

to address the challenges of *The Decade of Vision 2010-2020*—as recognized by Congress in H. Res. 366 in 2009—which include an aging population, disproportionate risk/incidence of eye disease in fast-growing minority populations, and the impact on vision from many chronic diseases and their treatments/therapies.

Despite the total FY2016-2019 funding increases of $120 million, NEI's enacted FY2019 budget of $797 million is just 14 percent greater than the pre-sequester FY2012 $702 million budget. Averaged over the seven fiscal years, the 2 percent annual growth rate is less than the average annual biomedical inflation rate of 2.8 percent, thereby eroding purchasing power, which in FY2019 is equivalent to FY2001. Maintaining the momentum of vision research is vital to vision health, as well as overall health and quality of life. Since the US is the world leader in vision research and training the next generation of vision scientists, the health of the global vision research community is at stake.

NEI LEADS IN GENETIC AND REGENERATIVE MEDICINE RESEARCH

As recently as the March 21, 2018, NEI 50th Anniversary Congressional Reception, NIH Director Francis Collins, MD, PHD stated the following about the NEI:

> "Due to the architecture, accessibility, and the elegance of the eye, vision research has always been a few steps ahead in biomedical research. Understanding the genetic basis of eye diseases has led the way for understanding the genetic basis of many common diseases."

The NEI has been a leader in genetics/genomics research and regenerative medicine.

- Genetics/Genomics: Vision researchers worldwide participating in NEI's Glaucoma Genetics Collaboration Heritable Overall Operational Database (NEIGHBORHOOD) Consortium have identified 133 genetic variants that predict within 75 percent accuracy a person's risk for developing glaucoma related to

elevated intraocular pressure (IOP). Among the 133 variants, 68 had not been previously linked to IOP, and their loci point to cellular processes, such as lipid metabolism and mitochondrial function, that contribute to IOP. By understanding these cellular processes that can increase IOP and cause optic nerve damage, clinicians may be able to make an earlier diagnosis and researchers may be able to develop neuroprotective therapies to potentially halt disease progression.

- 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.
- Regenerative Medicine: NEI is at the forefront of regenerative medicine with its Audacious Goals Initiative in Regenerative Medicine Initiative (AGI), which launched in 2013 with the goal of restoring vision. Initially asking a broad constituency of scientists within the vision community and beyond to consider what could be done if researchers employed this new era of biology, 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 quite 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.

- NEI plans a first-in-human clinical trial that would test a stem cell-based therapy from induced pluripotent stem cells (iPSC) to treat geographic atrophy, also known as the “dry” form of Age-related Macular Degeneration (AMD), the leading cause of vision loss among people age 65 and older. This trial converts a patient’s own blood cells to iPS 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.

CONGRESS MUST ROBUSTLY FUND THE NEI AS IT ADDRESSES THE INCREASING BURDEN OF VISION IMPAIRMENT AND EYE DISEASE

NEI’s FY2019 enacted budget of $797 million is just 0.55 percent of the $145 billion annual cost (inclusive of direct and indirect costs) of vision impairment and eye disease, which was projected in a 2014 Prevent Blindness study to grow to $317 billion—or $717 billion in inflation-adjusted dollars—by year 2050. Of the $717 billion annual cost of vison impairment by year 2050, 41 percent will be borne by the federal government as the Baby-Boom generation ages into the Medicare program. A 2013 Prevent Blindness study reported that direct medical costs associated with vision disorders are the fifth highest —only less than heart disease, cancers, emotional disorders, and pulmonary conditions. The U.S. is spending only $2.40 per-person, per-year for vision research, while the cost of treating low vision and blindness is at least $6,680 per-person, per-year. [http://costofvision.preventblindness.org/]

In a May 2016 *JAMA Ophthalmology* article, NEI-funded researchers reported that the number of people with legal blindness will increase by 21 percent each decade to 2 million by 2050, while best-corrected visual impairment will grow by 25 percent each decade, doubling to 6.95 million people—with the greatest burden affecting those 80 years or older. [http://jamanetwork.com/journals/jamaophthalmology/article-abstract/2523780?resultClick=1]

In an August 2016 *JAMA Ophthalmology* article, the Alliance for Eye and Vision Research (AEVR, NAEVR's educational foundation) reported that a majority of Americans across all racial and ethnic lines describe losing vision as having the greatest impact on their day-to-day life. Other studies have reported that patients with diabetes who are experiencing vision loss or going blind would be willing to trade years of remaining life to regain perfect vision, since they are concerned about their quality of life. [http://jamanetwork.com/journals/jamaophthalmology/article-abstract/2540516?resultClick=1]

Investing in vison health is an investment in overall health. NEI's breakthrough research is a cost-effective investment, since it leads to treatments and therapies that may delay, save, and prevent health expenditures. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life—as vision loss is associated with increased depression/accelerated mortality.

In summary, NAEVR requests FY2020 NIH funding of at least $41.6 billion and NEI funding of $850 million.

NAEVR, which serves as the "Friends of the NEI," is a 501(c)4 non-profit advocacy coalition comprised of 50-plus professional (ophthalmology and optometry), patient and consumer, private funding foundation, and industry organizations involved in eye and vision research. Visit NAEVR's Web site at www.eyeresearch.org