



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 2022 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
May 19, 2021**

EXECUTIVE SUMMARY

Good morning, and thank you for allowing me to testify. I am Dr. Michael Crair, Vice Provost for Research at Yale University and William Ziegler III Professor in the Departments of Neuroscience and Ophthalmology & Visual Science. I am pleased to testify on behalf of the National Alliance for Eye and Vision Research – or NAEVR – a 50-member 501(c)4 non-profit advocacy coalition serving as the “Friends of the National Eye Institute.”

NAEVR is grateful to Congress, especially this Subcommittee and its Senate counterpart, for the strong bipartisan support for NIH funding in recent years. The \$12.85 billion increase in funding from FY2016-FY2021 helped the NIH regain ground lost after a decade of effectively flat budgets.

Investments in NIH are essential for advancing our understanding of fundamental life and health sciences, contributing to innovation, and improving our quality of life. Long-term support for NIH also helps prepare the nation to combat unprecedented health threats, including COVID-19. To maintain momentum in FY2022, NAEVR strongly supports \$51 billion in NIH funding as proposed by President Biden, including no less than \$46.1 billion for NIH’s base program level budget, absent proposed funding for the

Advanced Research Projects Agency-Health (or ARPA-H), representing an increase of at least \$3.18 billion or 7.4%. This level of funding will support early-stage investigators, promising science across all Institutes and Centers, ensure continued Innovation Account funding established through the *21st Century Cures Act* for special initiatives, and allow the NIH's base budget to keep pace with biomedical inflation and grow by 5%.

NAEVR also urges one-time emergency funding for federal agency “research recovery” investments to mitigate pandemic-related disruptions without foregoing promising new science. NAEVR supports the bipartisan *Research Investment to Spark the Economy (RISE) Act* (H.R. 869/S. 289), which includes \$10 billion for NIH. Although pandemic-related lab closures impacted all researchers, early-stage investigators felt it most acutely. NAEVR’s educational foundation, the Alliance for Eye and Vision Research (AEVR), recently documented the pandemic’s impact on the training, collaborations, and career progression of young scientists in a Sept. 2020 video engaging 22 *Emerging Vision Scientists*, and in a publication in *JAMA Ophthalmology*.

Within the overall recommended budget increase for NIH, NAEVR also urges Congress to fund the NEI at \$900 million, a \$64.3 million or 7.7% increase over FY2021 that reflects both biomedical inflation and growth. Despite the \$160 million in total funding increases for NEI over FY2016-2021, the NEI enacted FY2021 budget of \$835.7 million is just 19% greater than the pre-sequester FY2012 funding of \$702 million. Averaged over those nine fiscal years, the 2.1% annual growth rate is less than the average annual biomedical inflation rate of 2.7%, effectively eroding scientists purchasing power. In fact, the purchasing power of NEI-funded scientists is less in FY2021 than it was in FY2012.

While NEI-funded investigators have made great strides, there is growing demand for additional breakthroughs from NEI-supported research to address the increasing burden of vision impairment and eye disease due to an aging population, the disproportionate risk/incidence of eye disease in fast-growing minority populations, and the impact on vision from numerous chronic diseases, such as diabetes. The COVID-19 pandemic has only exacerbated the burden of eye diseases, since students and the working age population have relied almost exclusively on electronic communication devices and e-learning platforms, which increases rates of myopia, dry eye, eye strain and other vision disorders. Maintaining the momentum of vision research is vital to vision health, as well as to overall health and quality of life. Since the US leads the world in vision research and training, the health of the global vision research community is also at stake.

NEI-FUNDED RESEARCH SAVES SIGHT AND RESTORES VISION

Previous federal investments have led to major advances in the prevention of vision loss and the restoration of vision. I'd like to provide a few examples of such research.

Audacious Goals Initiative: The NEI is at the forefront of regenerative medicine with its Audacious Goals Initiative (AGI), launched in 2013 with the goal of both preventing vision loss and restoring vision. AGI-funded consortia have developed innovative ways to image the visual system so that scientists can look at individual nerve cells in the eyes of patients to learn directly whether new treatments are effective. Another AGI-funded consortium has identified biological factors that promote the regeneration of neurons in the retina, with clinical trials of therapies derived from these vision restoring discoveries expected within the next decade.

Retinal Diseases: The NEI is also at the forefront of research into retinal diseases. NEI-funded scientists helped show that Vascular Endothelial Growth Factor (VEGF) stimulates abnormal blood vessel growth that occurs in 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 slow the development of blood vessels in the eye, delay vision loss, and improve the vision of patients suffering from AMD. Comparison trials of anti-VEGF drugs funded by the NEI provide clinicians and patients with vital information they need to choose their best treatment option. The “dry” form of AMD is the leading cause of vision loss among individuals age 65+. Since late 2019, NEI has been performing a first-in-human clinical trial that tests a stem cell-based therapy to treat “dry” AMD. This trial converts a patient’s own blood cells first to induce pluripotent stem cells, and then retinal pigment epithelial (RPE) cells, replacing the RPE cells in the eye that typically die in “dry” AMD, thereby rescuing vision.

Genetics/Genomics: The NEI is at the forefront of genetic discoveries and gene therapy approaches to both common and rare vision disorders. For example, the causes of AMD and glaucoma remain elusive—although most cases are not inherited, genetics plays an important role, and NEI-funded research identified many genetic risk factors for AMD and glaucoma, revealing underlying disease biology and the promise of improved therapies. NEI-funded research has also enabled discoveries of dozens of rare eye disease genes, including RPE65, which causes a form of congenital blindness called Leber’s Congenital Amaurosis (LCA). In late 2017, NEI sponsored research efforts on LCA enabled the commercialization of one of the first FDA-approved gene therapies. Remarkably, the same gene therapy technology is being used now in an FDA

authorized COVID-19 vaccine. These technologies form the basis of many new and emerging disease therapies, with NEI-funded research at the vanguard to enable these gene-based technologies.

Front-of-Eye Research: The NEI has launched an Anterior Segment Initiative (ASI) to study clinically significant, front-of-eye problems such as ocular pain and Dry Eye Disease, especially the pain, discomfort and disruptions in the tearing process associated with Dry Eye. The NEI's ASI will elucidate the neural pathways that contribute to normal and abnormal functioning of the ocular surface.

NEI RESEARCH ADDRESSES INCREASING BURDEN OF EYE DISEASE

NEI's FY2021 enacted budget of \$835.7 million is less than 0.5% of the \$177 billion annual cost of vision impairment and eye disease, which is projected to grow to \$317 billion—or \$717 billion in inflation-adjusted dollars—by 2050. Of that cost, 41% will be borne by the federal government as the Baby-Boom generation ages into the Medicare program. Direct medical costs associated with vision disorders are the fifth highest — exceeded only by heart disease, cancers, behavioral disorders, and pulmonary conditions. The U.S. spends only \$2.53 per-person, per-year for vision research, while treating low vision and blindness costs \$7,000 per-person, per-year.

In conclusion, investing \$51 billion in FY2022 NIH funding, with \$900 million for NEI-funded vision research, is an investment in the public's overall health, resulting in treatments and therapies that may delay, reduce, and prevent future costs. It will also increase productivity, help individuals to maintain their independence, and generally improve quality of life. I thank the Subcommittee for the opportunity to testify and for its support of biomedical and vision research.