

The Honorable Robert Aderholt
Chair
House Appropriations Subcommittee on
Labor, Health and Human Services,
Education, and Related Agencies
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Subcommittee on
Labor, Health and Human Services,
Education, and Related Agencies
Washington, DC 20515

The Honorable Tammy Baldwin
Chair
Senate Appropriations Subcommittee
on Labor, Health and Human Services,
Education, and Related Agencies
Washington, DC 20510

The Honorable Shelley Moore Capito
Ranking Member
Senate Appropriations Subcommittee
on Labor, Health and Human Services,
Education, and Related Agencies
Washington, DC 20510

August 16, 2024

Re: Vision Community Concerns with House Proposal Consolidating the National Eye Institute into a Broader Institute on Neuroscience and Brain Research

Dear Chairs Aderholt and Baldwin and Ranking Members DeLauro and Capito:

Over 90 million Americans 40 years of age or older are experiencing vision impairment. Nearly five million children are living with diagnosed vision conditions. The risk of developing eye disease is projected to double in the next twenty-five years. These sobering statistics compel us, the undersigned organizations that represent patients, providers, researchers, industry, and stakeholders to express our profound concern regarding the proposed drastic restructuring of the National Institutes of Health (NIH) and its potential negative impact on vision research.

As outlined in the recent *Reforming the National Institutes of Health: Framework for Discussion* report published by the Energy & Commerce (E&C) Committee (June 14, 2024), and subsequently included in the House Labor Health and Human Services (LHHS) FY25 Appropriations Bill, the consolidation of the National Eye Institute (NEI) into a broader *Institute on Neuroscience and Brain Research* poses a grave threat to the critical focus required to advance vision research and patient outcomes. Such a restructuring risks diluting the specialized attention and funding necessary for advancing our understanding and treatment of eye diseases.

The distinct and dedicated efforts of the NEI are crucial for addressing the unique challenges and needs of vision health. The proposed consolidation threatens to undermine the enormous progress made in vision research resulting in revolutionary breakthroughs in the treatment of macular degeneration and, diabetic retinopathy as well as other blinding diseases. Future innovative research that will lead to vision preservation or restoration for millions of Americans affected by vision impairment is at risk. While we recognize there may be an interest in NIH reforms, we urge Congress to have an open dialogue with stakeholders, hold public hearings, and provide opportunities for stakeholders to respond appropriately to formal recommendations before implementation.

Another crucial consideration is that many eye diseases, such as retinal vascular disorders, uveitis, corneal injuries and degenerations, and conditions affecting the ocular adnexae (like eye muscle issues, eyelid disorders, and dry eye syndromes), do not involve the central nervous system (CNS) or the peripheral nervous system (PNS). This makes them incompatible with being grouped alongside neurological diseases. This further underscores the incompatibility of consolidating the National Eye Institute with a broader Institute on Neuroscience and Brain Research, as it would blur the distinct focus needed for advancing vision research and treatment.

With this in mind, and without clear implications on the profound impact such a proposal would have on vision science and medical science as a whole, we strongly urge Congress to reject the proposed consolidation of the NEI into a new and broader *Institute on Neuroscience and Brain Research* as outlined in the E&C report and House LHHS FY25 Appropriations Bill.

The eye serves as an extraordinary model for medical research due to its unique characteristics. Its accessibility allows for non-invasive imaging and direct observation of cellular processes, while its direct connection to the brain through the optic nerve provides crucial insights into neurological functions and diseases. The eye's vascular network mirrors systemic conditions, making it a valuable window into broader health issues such as diabetes and hypertension. Moreover, the distinct cellular structures and functions within the eye offer unparalleled opportunities for studying cell biology, genetics, and regenerative medicine. These characteristics make vision research a linchpin for broader scientific discoveries and medical innovations.

Congress recognized the critical importance of vision research when it established the NEI in 1968. Since then, the NEI has driven significant advancements in medical research,

contributing greatly to the broader biomedical research community. Several notable achievements include:

- **Gene Therapy:** The NEI supported the development of Luxturna, the first FDA-approved gene therapy for an inherited disease. This groundbreaking treatment for Leber congenital amaurosis has paved the way for other gene therapies targeting vision and non-vision-related genetic disorders.
- **Stem Cell Research:** Vision scientists at the NEI have made significant strides in the development and use of adult stem cells for regenerative medicine. For instance, stem cell-based therapies for age-related macular degeneration (AMD) are currently undergoing clinical trials, offering hope for millions affected by this leading cause of blindness.
- **Imaging Technologies:** The NEI has been instrumental in advancing imaging technologies such as Optical Coherence Tomography (OCT). OCT allows for non-invasive, high-resolution imaging of retinal structures, revolutionizing the diagnosis and management of various eye diseases, including glaucoma and diabetic retinopathy.
- **Artificial Intelligence (AI):** The integration of AI into vision research has led to early and more accurate diagnoses of eye diseases. AI algorithms can now detect diabetic retinopathy, AMD, and other conditions from retinal images, improving patient outcomes through timely intervention.
- **Neurological Research:** The eye is a unique model for studying neurological disorders. Research supported by the NEI has shown that changes in the retina can reflect early signs of diseases such as Alzheimer's and Parkinson's, offering potential pathways for early diagnosis and intervention.

The NEI's status level within the NIH is essential to ensuring that vision research continues to advance. With the prevalence of myopia projected to impact over 50% of the global population by 2030 and the incidence of age-related macular degeneration, glaucoma, diabetic retinopathy, and vision loss expected to double by 2050, research is needed to improve diagnosis, treatment, and care for people who are impacted by these diseases that fundamentally change the way people experience the world.

We strongly oppose the proposed consolidation and advocate for maintaining the NEI as a distinct and dedicated institute within the NIH. This will not only uphold the momentum of groundbreaking advancements but also reflect the crucial importance of vision research in improving overall health outcomes. In addition, we respectfully urge Congress to continue its investment and recognition of the importance of vision research by funding the NEI as a standalone institute within NIH at \$1 billion in FY25.

Thank you for your attention to this critical matter. We hope you will champion the cause of vision research by supporting the continued independence and prioritization of the NEI within the NIH. The preservation of the NEI as a distinct entity is not just about maintaining administrative structures; it is about ensuring that the groundbreaking and life-changing research conducted in the field of vision science continues to receive the focused attention and resources it requires.

The NEI's specialized focus has led to significant advancements in understanding and treating eye diseases, which in turn have broader implications for overall health and medical research. By maintaining the NEI's independence, we can continue to foster innovations that improve the quality of life for millions of Americans. We urge you to consider the far-reaching consequences of the proposed consolidation and to support the NEI in its mission to advance vision research and protect the visual health of the nation.

Sincerely,

The National Alliance for Eye and Vision Research

Serving as friends of the National Eye Institute

Undersigned Organizations (92):

For questions or additional information, please contact Dan Ignaszewski, Executive Director for the National Alliance for Eye and Vision Research, at Dan@eyersearch.org or 202-742-1885.

Albert Einstein College of Medicine, Montefiore Medical System
American Academy of Ophthalmology
American Academy of Optometry
American Association of Ophthalmic Oncology and Pathology
American Association of pediatric ophthalmology and strabismus (AAPOS)
American Glaucoma Society
American Macular Degeneration Foundation
American Society of Retina Specialists
American Uveitis Society
Association of Schools and Colleges of Optometry
Association of University Professors of Ophthalmology (AUPO)
Atrium Health Wake Forest Baptist
Atrium Health Wake Forest Baptist Eye Center
Bascom Palmer Eye Institute / University Of Miami
Baylor College of Medicine
Boston University
BrightFocus Foundation
Case Western Reserve University / University Hospitals
Cornea Society
Dean McGee Eye Institute/Department of Ophthalmology/University of Oklahoma
College of Medicine
Department of Ophthalmology and Visual Sciences, University of Wisconsin School of
Medicine and Public Health
Department of Ophthalmology University of Tennessee Health Science Center
Department of Ophthalmology, Louisiana State University
Doheny Eye Institute
Emory University Department of Ophthalmology
Eye Bank Association of America
EyeSight Foundation of Alabama
Fight for Sight
Foundation Fighting Blindness
Fraser Eye Care
Geisel School of Medicine at Dartmouth
Georgetown University/MedStar Health Department of Ophthalmology
Hamilton Eye Institute, University of Tennessee Health Sciences
Herbert Wertheim School of Optometry and Vision Science, University of California
Berkeley

Illinois College of Optometry
Institute of Ophthalmology and Visual Science, Rutgers New Jersey Medical School
International Society of Ocular Oncology
LightHouse for the Blind and Visually Impaired
Lions Clubs International Foundation
Loyola University Medical Center
Marshall B. Ketchum University
Mayo Clinic Department of Ophthalmology
Michigan Society of Eye Physicians and Surgeons
New England College of Optometry
New York Eye and Ear Infirmary of Mount Sinai
New York Eye Institute
New York University Grossman School of Medicine
Northwell Health Eye Institute
Northwestern University, Feinberg School of Medicine, Department of Ophthalmology
NYU Langone Health
Ochsner Health
Oregon Health & Science University - Casey Eye Institute
Pediatric Eye Disease Investigator Group (PEDIG)
Prevent Blindness
Prevent Blindness Ohio
Research to Prevent Blindness
Retina Associates of Michigan
Retina Specialists of Michigan
Rocky Mountain University
Rush University Medical Center
SF LightHouse for the Blind and Visually Impaired
State University of New York College of Optometry
Texas Tech University HSC
The Association for Research in Vision and Ophthalmology
The Dry Eye Foundation
The Ohio State University College of Optometry
The Smith-Kettlewell Eye Research Institute
Therapeuticvision Inc.
Thomas Jefferson University
Tufts University School of Medicine

University of Alabama at Birmingham School of Optometry
University of Arizona College of Medicine Phoenix Dept Ophthalmology
University of California, Irvine. Gavin Herbert Eye Institute
University of California, San Diego
University of California, San Francisco Department of Ophthalmology
University of Florida, Jacksonville
University of Iowa Hospitals & Clinics, Ophthalmology Dept.
University of Michigan/Kellogg Eye Center
University of Missouri
University of Nebraska Medical Center - Truhlsen Eye Institute
University of Pennsylvania Perelman School of Medicine
University of Pittsburgh School of Medicine
University of South Florida Department of Ophthalmology
University of Southern California Keck School of Medicine
USC Roski Eye Institute
Usher Syndrome Coalition
Vanderbilt University Medical Center
Vision Health Advocacy Coalition
Vision Sciences Society (VSS)
VisionServe Alliance
Washington University School of Medicine
Wills Eye Hospital