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

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

May 23, 2025

# **Opposition to Proposed FY26 Budget Cuts and NIH/NEI Consolidation**

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

On behalf of the more than 90 million Americans over 40 who experience vision impairments, the nearly five million children living with a diagnosed vision condition, and those at risk for or who have not yet been diagnosed with a vision disorder, the undersigned organizations representing patients, providers, researchers, industry, and stakeholders thank the Committee's bipartisan support for investment in the National Institutes of Health (NIH), and, specifically, the National Eye Institute (NEI). We urge you to continue the commitment to build on the investments in research that are leading to improved patient care and outcomes as we manage the emerging epidemic of vision loss in the United States. Specifically, as you draft the Labor, Health and Human Services, Education, and Related Agencies (LHHS) appropriations bill for FY26, we respectfully request the Committee to maintain vision as a priority by ensuring the NEI remains a dedicated institute within NIH, reject the blanket 15% indirect rate cap proposal on NIH grants, and include \$1B for the NEI to continue to build on the tremendous successes within vision research.

## Vision is Foundational to Human Experience and Health

While we acknowledge the complexities of the current budgetary landscape, we want to emphasize the critical importance of ensuring vision research remains a dedicated priority within NIH. Vision is the sense through which we most directly experience the world. It enables independence, mobility, connection, and supports emotional well-being. Americans consistently rank vision loss as one of their most feared health outcomes, above the loss of memory, speech, or limb.

The stakes are high: the number of Americans affected by macular degeneration, glaucoma, and diabetic eye disease is expected to double in the next 25 years. Nearly 5 million children live with a diagnosed vision condition, and many go undiagnosed. Myopia rates are surging across all age groups, with incidence projected to eclipse 50% of the global population by 2030 and the National Academies of Sciences, Engineering and Medicine (NASEM) has emphasized we must improve understanding and treatments for this disease. With these figures, it's easy to understand why the annual economic burden of vision disorders continues to increase and is projected to exceed \$199 billion in 2025 (\$865 per American) while federal investment in vision research remains alarmingly low—\$896.5 million since FY23 (\$2.65 per American).

The NEI's entire FY25 budget—\$896.55 million—represents just 0.45% of the economic burden of vision disorders. Increasing that investment to \$1 billion in FY26 is a cost-effective and life-changing step that represents a smart investment in our future by:

- Reducing long-term healthcare costs through innovation and improved care,
- Preventing avoidable blindness and disability,
- Supporting aging populations, and
- Advancing whole-body health through precision diagnostics and AI-enabled screening.

### Vision Research Leads in Innovation, Impact, and Cross-System Discovery

The NEI and vision research is a model of research excellence and innovation. The targeted investment strategy and focus on the eye has advanced transformational science that benefits not only the field of ophthalmology and optometry, but also broader medicine. Landmark NEI-supported achievements include:

- First FDA-approved gene therapy (Luxturna) for an inherited disease—transforming the treatment landscape for childhood blindness and unlocking new pathways for gene therapy across medicine.
- First FDA-approved autonomous AI diagnostic tool (IDx-DR) for diabetic retinopathy—pioneering safe and accessible disease screening in primary care and reducing vision loss among underserved populations.
- Development of optical coherence tomography (OCT)—a noninvasive imaging platform now foundational to eye care and increasingly used in cardiology and neurology.
- Research leading to regenerative therapies for macular degeneration, including adult stem cell-based corneal repair, and optic nerve regeneration.
- Research leading to advancements in gene editing for inherited retinal disorders to improve early-stage treatment of conditions like retinitis pigmentosa, Stargardts disease, and others.
- Advancements in artificial intelligence (AI)—training algorithms on retinal images are putting eye research at the forefront of precision medicine and non-invasive diagnostics.

#### The Eye is Not Just a Window into the Brain-It's a Gateway to Whole-Body Health

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.

While the eye provides a direct extension of the central nervous system through the optic nerve, it is much more than a window into the brain and is now proving its role in early diagnosis and treatment for broader health. The eye is a critical frontier for "oculomics"—the study of how ocular imaging and biomarkers can reveal systemic health conditions, including diabetes, hypertension, cardiovascular disease, kidney disease, and neurodegenerative disorders.

Recent research has demonstrated that:

• Retinal imaging can detect early signs of Alzheimer's and Parkinson's disease before clinical symptoms emerge.

- Eye scans combined with AI can predict stroke risk and cardiovascular disease with accuracy comparable to traditional blood tests.
- Inflammatory markers and vascular changes in the eye offer insights into autoimmune conditions, diabetes, and even long COVID.

The NEI's unique focus enables this systems-level innovation, which would be significantly hindered under a broader institute focused on neuroscience and brain research and continues to emphasize the importance of maintaining a focus on vision research.

## Consolidation Would Undermine Progress, Dilute Funding, and Set Back Science and Patient Care

The NEI was created by Congress in 1968 by separating the vision research programs from the National Institute of Neurological Diseases and Blindness (NINDB), now known as the National Institute of Neurological Disorders and Stroke (NINDS). This separation recognized that eye and vision science warranted a dedicated institute with its own mission, funding, and research agenda, distinct from the broader neurological focus of NINDB (now NINDS). The creation of NEI marked a pivotal moment in federal support for vision research and laid the foundation for decades of innovation in eye health, and now, proving its role in systemic health.

The President's FY26 Budget Proposal revives the recommendation from the House FY25 Labor-HHS bill: to dissolve the NEI and merge it into a broader Institute on Neuroscience and Brain Research, which would take us back nearly 60 years in progress, eliminating the dedicated focus on vision. It's also important to understand that many eye diseases, such as retinal vascular disorders, uveitis, corneal injuries and degenerations, dry eye disease, and conditions affecting the ocular adnexae (like eye muscle issues, eyelid disorders, and dry eye syndromes), as well as many pediatric ocular conditions do not involve the central nervous system (CNS) or the peripheral nervous system (PNS). This makes them incompatible with being grouped alongside neurological diseases and may likely be eliminated as a focus area in a Neuroscience and Brain Institute. This further underscore 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.

The risks of consolidation are clear:

- Loss of scientific focus and strategic grant review tailored to the unique biology of vision.
- Dilution of limited funds into broader neuroscience areas that already benefit from existing institutes.
- Elimination of vital infrastructure, such as NEI-led clinical trials networks, specialized advisory councils, and targeted research programs.
- Elimination of research and progress on vision conditions that are specifically tied to the central or peripheral nervous system.
- Disruption of translational pipelines for therapies nearing clinical use.

Maintaining the NEI's independence ensures that eye research receives the dedicated scientific attention and resources necessary to preserve sight and health across the lifespan.

#### Proposed 15% Indirect Cost Cap Would Undermine Research Infrastructure Nationwide

In addition to the proposed NIH budget cuts and NEI consolidation, we are alarmed by the plan to continue the policy that would cap indirect cost reimbursement at 15% for all NIH-funded grants. This proposal continues to threaten the foundational infrastructure that enables research in vision science and across all biomedical disciplines and has already been a point of significant bipartisan concern.

Indirect costs, also known as Facilities and Administrative (F&A) costs, are essential for:

- Maintaining safe and up-to-date laboratory spaces,
- Supporting critical staff and research administrators,
- Ensuring compliance with federal regulations and bioethics standards,
- Providing secure IT infrastructure and research data management,
- Covering utilities, custodial services, and administrative oversight.

These are not luxuries—they are the backbone of research operations at universities, academic medical centers, and independent research institutions across the country. For most research institutions, negotiated indirect cost rates with the federal government reflect actual, audited expenses—rates that average significantly higher than 15%. Imposing an arbitrary nationwide cap would result in billions in unreimbursed costs, forcing institutions to cut research support and staff, try to absorb deficits, and potentially limit participation in NIH programs altogether.

The United States has long maintained a global dominance in research. This policy alone will have a devastating impact on research infrastructure and is already positioning other countries like China and others in Europe and Asia to attract successful researchers as they look to close the gap. These caps will also effectively reduce and eliminate pathways for early career scientists to get into and maintain a career in academic research, devastating America's role in future advancements.

This policy would be particularly devastating for some of the largest employers in many states and for institutions serving rural, under-resourced, or minority communities, further widening disparities in access to research funding and participation.

We urge Congress to reject the proposed 15% cap on indirect cost reimbursement and instead support a measured, bipartisan approach to any future policy changes on these expenses. Indirect cost rates should continue to be negotiated transparently between the federal government and research institutions through established and evidence-based processes, not through blunt policy instruments.

#### **Our Requests to Congress**

In light of these threats and opportunities, we respectfully request that Congress:

- Reject the proposals to consolidate the NEI into a Neuroscience and Brain Research Institute and protect NEI and vision research as a dedicated priority at the institute level within NIH. Engage with stakeholders and research the impacts of any proposed structural changes on patient populations and research investment at NIH before implementation.
- Reject the Administration's proposed 37% cut to NIH funding, which would stall critical medical innovation and reverse decades of progress and maintain bipartisan support to appropriately fund biomedical research.
- Reject the 15% cap on indirect F&A costs and work with stakeholders to establish a measured approach to any indirect rate reforms to limit the impact on the medical research infrastructure and maintain America's global leadership.
- Provide \$1 billion for the NEI in FY26, to ensure continued advancement of front- and back-of-the-eye
  research, support systemic health discovery, and address the accelerating public health crisis of vision
  loss.

Thank you for your leadership in championing biomedical research and for your continued support of the National Eye Institute and vision researchers across our country. For more information or to discuss this request, please contact Dan Ignaszewski, Executive Director of the National Alliance for Eye and Vision Research (NAEVR), at Dan@eyeresearch.org or 202-742-1885.

Sincerely,

## Friends of the National Eye Institute

- 1. Advancing Sight Network
- 2. Alliance for Aging Research
- 3. American Academy of Ophthalmology
- 4. American Academy of Optometry
- 5. American Association of Ophthalmic Oncology and Pathology
- 6. American Association of pediatric ophthalmology and strabismus (AAPOS)
- 7. American Glaucoma Society
- 8. American Macular Degeneration Foundation
- 9. American Uveitis Society
- 10. Ascento-cda
- 11. Association for Education and Rehabilitation of the Blind and Visually Impaired
- 12. Association of schools and Colleges of Optometry
- 13. Association of University Professors of Ophthalmology
- 14. Bascom Palmer Eye Institute
- 15. BrightFocus Foundation
- 16. Case Western Reserve School of Medicine Department of Ophthalmology and Visual Sciences
- 17. Casey Eye Institute, Oregon Health & Science University
- 18. Cincinnati Eye Bank
- 19. Cornea Society
- 20. Dean McGee Eye Institute
- 21. Department of Ophthalmology and Visual Sciences, University of Wisconsin
- 22. Doheny Eye Institute
- 23. Duke University
- 24. East Tennessee Lions Eye Bank
- 25. Emory University Department of Ophthalmology
- 26. Eye Bank Association of America
- 27. Fight for Sight
- 28. Flaum Eye Institute, University of Rochester Medical Center
- 29. Foundation Fighting Blindness
- 30. Future Leaders in Sight (FLIS)
- 31. Gavin Herbert Eye Institute, University of California, Irvine
- 32. Geisel School of Medicine at Dartmouth
- 33. Georgia Eye Bank

- 34. Glaucoma Research Foundation
- 35. Hamilton Eye Institute, University of Tennessee Health Sciences
- 36. Icahn School of Medicine at Mount Sinai
- 37. Illinois College of Optometry
- 38. Indiana University School of Optometry
- 39. International Society of Ocular Oncology
- 40. Iowa Lions Eye Bank
- 41. Kellogg Eye Center/University of Michigan Department of Ophthalmology and Visual Sciences
- 42. Kresge Eye Institute, Wayne State University
- 43. LightHouse for the Blind and Visually Impaired
- 44. Lighthouse Louisiana
- 45. Lions Clubs International Foundation
- 46. Lions Eye Bank of Nebraska
- 47. Lions eye Bank of the North East
- 48. Lions World Vision Institute
- 49. Loma Linda University Health Preventive Medicine Department
- 50. Marshall B. Ketchum University
- 51. Medical College of Georgia at Augusta University
- 52. Medical College of Wisconsin
- 53. National Alliance for Eye and Vision Research
- 54. New England College of Optometry
- 55. New Mexico Lions Eye Bank
- 56. New York Eye and Ear Infirmary of Mount Sinai
- 57. New York University Grossman School of Medicine
- 58. Northwell Health Eye Institute
- 59. Northwestern Medicine
- 60. Northwestern University, Feinberg School of Medicine, Department of Ophthalmology
- 61. NPHP1 Family Foundation
- 62. OHSU Casey Eye Institute
- 63. Oklahoma Lions Eye Bank
- 64. Prevent Blindness
- 65. Prevent Blindness Ohio
- 66. Prevention of Blindness Society of Metropolitan Washington
- 67. Research to Prevent Blindness
- 68. Rocky Mountain University
- 69. Rush University Medical Center
- 70. Save Sight Now
- 71. Saving Sight
- 72. Scheie Eye Institute, University of Pennsylvania Perelman School of Medicine
- 73. Sjogren's Foundation

- 74. The American Association of Ophthalmic Oncologists and Pathologists
- 75. The American Society of Ophthalmic Trauma
- 76. The American Society of Retina Specialists
- 77. The Association for Research in Vision and Ophthalmology (ARVO)
- 78. The Dry Eye Foundation
- 79. The Eye Bank of Kentucky
- 80. The Eye-Bank for Sight Restoration
- 81. The EyeSight Foundation of Alabama
- 82. The Glaucoma Foundation
- 83. The Macula Society
- 84. The Ohio State University College of Optometry
- 85. The Retina Society
- 86. The Smith-Kettlewell Eye Research Institute
- 87. The Vision Council
- 88. University of Alabama at Birmingham School of Optometry
- 89. University of North Texas Health science center
- 90. University of Pittsburgh School of Medicine
- 91. University of Southern California
- 92. University of Utah John Moran Eye Center
- 93. University of Washington
- 94. University of Wisconsin Department of Ophthalmology and Visual Sciences
- 95. USC Department of Ophthalmology
- 96. Usher Syndrome Coalition
- 97. Utah Lions Eye Bank
- 98. Verum Research, LLC
- 99. Vision Health Advocacy Coalition
- 100. Vision Sciences Society
- 101. VisionFirst Indiana Lions Eye Bank
- 102. VisionGift
- 103. VisionServe Alliance
- 104. Wills Eye Hospital