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Testimony on behalf of the American Society of Human Genetics,
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Prepared for the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies,
Committee on Appropriations, United States House of Representatives

Fiscal Year 2026 Funding for the National Institutes of Health, Department of Health and Human Services

April 9, 2025

As the world's largest organization for human genetics and genomics professionals, the American Society of Human Genetics (ASHG) thanks the Subcommittee on behalf of its members for its continued strong leadership in supporting biomedical research through ensuring robust funding for the National Institutes of Health (NIH). It is now more important than ever for the United States to invest in biomedical research and scientific innovation. Sustained and predictable growth in NIH funding is critical to ensuring that resources keep pace with scientific opportunity. The Ad Hoc Group for Medical Research, as a coalition of biomedical research organizations which includes ASHG, recommends the appropriation of $51.3 billion for NIH in order to support meaningful growth and progress to make America healthier and so essential progress is not lost on current ongoing research. Additionally, ASHG asks that the Subcommittee preserve Section 224 of the FY 2024 Appropriations Act in the FY 2026 appropriations bill to avoid abrupt changes to NIH funding policies for Facilities and Administration (F&A) costs that would severely limit essential resources for the biomedical research ecosystem.[1]

Recent Advances in Human Genetics and Genomics Due to Federal Investment

Over the past year, human genetics and genomics research has made incredible strides, leading to revolutionary breakthroughs and treatments that are improving public health and quality of life for people across the nation. The *All of Us* Research Program, supported by the NIH, has now amassed genomic data from over 400,000 participants from all over the United States, identifying over 275 million previously unreported genetic variants, as well as genetic variants that are robustly associated with 117 different diseases.[2] *All of Us* data has also been used to facilitate early screening and prevention of cardiovascular

[1] https://grants.nih.gov/grants/guide/notice-files/NOT-OD-24-110.html
[2] The All of Us Research Program Genomics Investigators. "Genomic data in the All of Us Research Program." *Nature* **627**, 340–346 (2024). https://doi.org/10.1038/s41586-023-06957-x

disease and heart failure,[3] among countless other advances. Researchers have also used this data to find genetic variants that significantly reduce the risk of chronic and end-stage kidney disease in those with known high-risk variants, highlighting the potential for genetic therapies to manage or prevent kidney conditions in high-risk populations.[4] The unprecedented insights collected through the *All of Us* research dataset have helped to improve diagnoses, prevention, and treatments, and will lead to even more revolutionary breakthroughs in the future as *All of Us* continues to collect data, leading to enhanced understandings of human genetics and increased public health benefits for all Americans. The Undiagnosed Disease Network (UDN), supported by the National Institute of Neurological Disorders and Stroke (NINDS), has also made substantial strides leading to the description of over 100 new conditions, as well as over 200 rare disease diagnoses in 2024 alone.[5, 6] Not only do these diagnoses provide hope and support to families, but they also offer the possibility of future treatments to these families and any others who may unknowingly be affected by one of these rare diseases.

Human genetics and genomics research has also contributed to remarkable progress in gene therapy and genome editing. For example, gene-editing technologies have been able to restore vision to patients with inherited, severe early-onset vision loss.[7] Furthermore, physicians have been able to use whole-genome sequencing (WGS) to improve diagnostic precision, enhance treatment strategies, and overall improve clinical benefit and quality of care for children in cancer centers.[8] Researchers have also been able to optimize polygenic risk scores (PRS) – estimates of an individual's risk for a disease or trait based on their genes – for a range of chronic diseases, including diabetes, cardiovascular diseases, and multiple forms of cancer, which will improve detection, treatment, and outcomes for these diseases that impact people from across the United States.[9]

These advances have already helped many and will continue to contribute to our fundamental understanding of genetics, saving countless lives across the United States. Such advances are only possible due to our strong federal investment in human genetics and genomics. Sustained funding for NIH is vital to furthering our understanding of genetic contributions to health and disease, and will lead to many more revolutionary scientific and technological advancements to improve human health.

Economic Impact of Human Genetics and Genomics

Not only does federal investment in genetics and genomics improve health outcomes, but it also drives substantial economic growth. ASHG's 2021 commissioned report found that the human genetics and genomics sector supports approximately 850,000 jobs and contributes $265 billion to the U.S. economy each

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[3] Shetty, N.S. *et al.* (2024) 'High-proportion spliced-in titin truncating variants in African and European ancestry in the all of us research program', *Nature Cardiovascular Research*, 3(2), pp. 140–144. doi:10.1038/s44161-023-00417-5.
[4] Hung, A.M. *et al.* (2023) 'Genetic inhibition of APOL1 pore-forming function prevents APOL1-mediated kidney disease', *Journal of the American Society of Nephrology*, 34(11), pp. 1889–1899. doi:10.1681/asn.0000000000000219
[5] https://undiagnosed.hms.harvard.edu/wp-content/uploads/2024/04/UDN-Quarterly-Report_Spring-2024.pdf
[6] https://undiagnosed.hms.harvard.edu/wp-content/uploads/2024/10/UDN-Quarterly-Report-Fall-2024.pdf
[7] Pierce, E. A. *et al.* Gene editing for CEP290-associated retinal degeneration. *New England Journal of Medicine* **390,** 1972–1984 (2024).
[8] Hodder, A. *et al.* Benefits for children with suspected cancer from routine whole-genome sequencing. *Nature Medicine* **30,** 1905–1912 (2024).
[9] Lennon, N. J. *et al.* Selection, optimization and validation of ten chronic disease polygenic risk scores for clinical implementation in diverse us populations. *Nature Medicine* **30,** 480–487 (2024).

year.[10] Federal funding for human genetics and genomics research also leads to a tremendous return on investment, with the U.S. government receiving more than $4.75 for each $1 invested. Researchers in every state and nearly every congressional district benefit from NIH funding, which, in turn, fosters job creation and delivers a significant return on investment, ultimately supporting a robust and thriving economy.[11] NIH-funded research has also spurred the development of genetic technologies, diagnostic tools, and precision medicine initiatives, leading to significant growth in biotechnology, healthcare, and data science industries.

Outside of job creation, human genetics and genomics research is reducing healthcare costs by enabling early detection and prevention of diseases. For example, a new breast cancer risk assessment tool outperforms previous tools with doubled accuracy - innovations like this help to enable early detection and preventative care, decreasing later therapeutic costs on patients, taxpayers, and the healthcare system as a whole.[12]

F&A costs are also vital to sustaining the research enterprise in the United States and play a key role in supporting the economy. The U.S. has many of the best research universities in the world, and these institutions rely on F&A costs, which support the critical infrastructure required to conduct groundbreaking research. These costs are used to maintain state-of-the-art laboratories, protect sensitive genomic data, and ensure compliance with all federal regulations and ethical and safety standards. A sudden and significant reduction in funding would have a profound and immediate effect not only on biomedical research, but on local, state, and national economies as well, putting thousands out of work and delaying lifesaving treatments and research advances.

Research Training Pipeline and U.S. Scientific Competitiveness

The United States has long been a global leader in biomedical research, thanks to Congress's long-standing bipartisan support. However, maintaining this position requires continuous and increasing investments in the scientific workforce and research infrastructure. Countries like China and the United Kingdom are increasing their federal investments in genomics and precision medicine, posing a challenge to our nation's historical leadership and competitiveness in this field.

The F&A funding included in NIH grants to universities across the country plays a crucial role in supporting the next generation of scientists, as well as the next generation of American leadership in science and technology. Universities and academic research centers use these funds to support the research ecosystem, ensuring that young scientists are able to pursue a research career and contribute to cutting-edge genomics research, even in non-academic settings. Reducing federal support for F&A costs poses a threat to graduate students that depend on federal funding to carry out groundbreaking research and may drive universities to cut funding for these students or their programs altogether. Furthermore, limiting F&A reimbursements weakens universities' ability to offer competitive research opportunities, which makes it far more difficult to attract and retain top talent in the United States. It is vital for the research training pipeline in the United States to remain robust, so that American researchers and institutions can continue to lead global scientific and technological advances. By preserving existing law, Section 224 of the FY 2024

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[10] https://www.ashg.org/wp-content/uploads/2021/05/ASHG-TEConomy-Impact-Report-Final.pdf

[11] https://www.faseb.org/science-policy-and-advocacy/federal-funding-data

[12] Mabey, B. *et al.* Validation of a clinical breast cancer risk assessment tool combining a polygenic score for all ancestries with traditional risk factors. *Genetics in Medicine* **26,** 101128 (2024).

Appropriations Act, Congress can ensure that U.S. institutions remain competitive and continue to attract the brightest minds to drive innovation in human genetics and genomics research.

Summary

ASHG strongly urges the Subcommittee to appropriate $51.3 billion for NIH's base budget in FY 2026 and to preserve NIH funding policies for Facilities and Administration (F&A) costs, as described in Section 224 of the FY 2024 Appropriations Act, in the FY 2026 appropriations bill. This will ensure continued progress in human genetics and genomics, drive economic growth, and sustain the U.S.'s global competitiveness in biomedical research. We thank the Subcommittee for its continued support of biomedical research and health for all Americans, and look forward to working together to advance scientific discovery in FY 2026 and beyond.

The American Society of Human Genetics (ASHG), founded in 1948, is the primary professional membership organization for human genetics specialists worldwide. The Society's nearly 8,000 members include researchers, clinicians, genetic counselors, nurses, and others who have a special interest in the field of human genetics.