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

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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, a coalition of biomedical research organizations which includes ASHG, recommends the appropriation of $51.3 billion for NIH, and $1.7 billion for the Advanced Research Projects Agency for Health (ARPA-H) in order to support meaningful growth and progress to make America healthier and to ensure that essential progress is not lost on current ongoing research. To ensure continued progress, it is essential to prevent disruptions to NIH grants that include foreign subawards. Regarding the proposed restructuring of NIH, ASHG looks forward to working with Congress as you hold hearings and engage with the public to review these reorganization ideas. 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.

1. **The *All of Us* Research Program**. This program, supported by the NIH, has now amassed genomic data from over 400,000 participants from all over the United States, identifying more than 275 million previously unreported genetic variants, as well as genetic variants that are robustly associated with 117 different diseases, and thus, can be used to predict risk of disease and develop targeted interventions or treatments.[2] For example, *All of Us* data has been used to facilitate early screening and prevention of cardiovascular 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

[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
[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.

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 has helped to improve diagnoses, prevention, and treatments, and will lead to future revolutionary breakthroughs as *All of Us* continues to collect data, leading to enhanced understandings of human genetics and increased public health benefits for all Americans. Indeed, researchers have been able to use this data 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.[5]

2. **The Undiagnosed Disease Network (UDN).** The 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.[6,7] 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.

3. **Gene Therapy and Gene Editing.** Human genetics and genomics research has also contributed to remarkable progress in gene therapy and genome editing. Researchers at the Children's Hospital of Philadelphia, in collaboration with partners across the country, have developed a customized gene-editing therapy that, in the past year, has been shown to effectively treat a rare genetic disease with a 50% mortality rate in young infants.[8] Gene-editing technologies have also been able to restore vision to patients with inherited, severe early-onset vision loss.[9] Furthermore, physicians have been able to use whole-genome sequencing (WGS) to improve diagnostic precision, enhance treatment strategies, and improve clinical benefit and quality of care for children in cancer centers.[10]

These advances have already helped many people 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 research. Sustained funding for NIH and ARPA-H 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

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[4] 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] 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).

[6] https://undiagnosed.hms.harvard.edu/wp-content/uploads/2024/04/UDN-Quarterly-Report_Spring-2024.pdf

[7] https://undiagnosed.hms.harvard.edu/wp-content/uploads/2024/10/UDN-Quarterly-Report-Fall-2024.pdf

[8] Musunuru, K., et al. (2025). Patient-specific in vivo gene editing to treat a rare genetic disease. *The New England Journal of Medicine*. https://doi.org/10.1056/NEJMoa2504747

[9] Pierce, E. A. *et al.* Gene editing for CEP290-associated retinal degeneration. *New England Journal of Medicine* **390,** 1972–1984 (2024).

[10] Hodder, A. *et al.* Benefits for children with suspected cancer from routine whole-genome sequencing. *Nature Medicine* **30,** 1905–1912 (2024).

the U.S. economy each year.[11] Federal funding for human genetics and genomics research 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.[12] 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.[13]

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.

Facilities and Administrative (F&A) Costs:

The F&A funding included in NIH grants is used by universities and academic research centers to support the research enterprise, enabling young scientists to pursue research careers and contribute to cutting-edge genomics research, even outside academia. The U.S. has many of the best research universities in the world, and these institutions rely on F&A costs to support the infrastructure required to conduct groundbreaking research, including state-of-the-art laboratories, protecting sensitive genomic data, and ensuring 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 of staff employed by universities out of work in addition to delaying lifesaving treatments and research advances.

Reducing federal support for F&A also may force universities to scale back funding for graduate students or cut graduate programs entirely. 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 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.

International Partnerships and Collaboration

The human genetics and genomics community is a global enterprise, with data sharing and international collaborations to better understand the full breadth of human genetic variation. Recent

[11] https://www.ashg.org/wp-content/uploads/2021/05/ASHG-TEConomy-Impact-Report-Final.pdf
[12] https://www.faseb.org/science-policy-and-advocacy/federal-funding-data
[13] 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).

changes to the NIH policy on foreign subawards have the potential to impact the future of global health partnerships. Researchers working on disease-specific populations work with laboratories and hospitals outside of the United States – some of which can only be done in specific regions – to elucidate our understanding of genetic risk factors that contribute to disease. For example, more than 100 million people around the globe live with sickle cell trait, which affects one to three million Americans alone.[14] One abnormal copy of the hemoglobin gene is enough to increase the risk for severe blood clots in individuals with this risk variant. A study published by the National Human Genome Research Institute (NHGRI) involving data from over four million participants from around the world highlights that genetic carriers of sickle cell trait exist well beyond individuals of African origin, which was once assumed, and emphasizes the importance of global partnerships and collaborations to contribute to the SCD knowledge base and to improve millions of lives.[15] A lapse in funding for foreign subawards would have long-lasting, detrimental effects on the field of global health, hindering progress in understanding population-specific diseases, therapies, and treatments. As these policies are implemented at NIH, ASHG urges the Committee to ensure there is no disruption to existing NIH grants and cooperative agreements in process and up for renewal while the NIH works to implement a new system to review foreign subawards.

Advisory Committee Termination

To fully realize the promise of genetics and genomics research for mitigating the impacts of rare diseases, federal investments in research must be matched by governmental commitments to applying scientific developments to clinical practice. ASHG is deeply concerned about recent changes across the Department of Health and Human Services (HHS) that have led to the termination of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) and strongly urges Congress to protect this Committee's important work. Prior to its termination, ACHDNC would advise on universal newborn screening programs for states which are based on evidence that early detection and treatment can significantly improve health outcomes. Elimination of this Advisory Committee will have a detrimental impact on the health of newborns and children across the United States.

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. The Society also asks the Subcommittee to ensure that there are no disruptions to NIH grants that include foreign subawards. 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.

[14] https://www.hematology.org/education/patients/anemia/sickle-cell-trait#:~:text=Sickle%20cell%20trait%20occurs%20when,10%20percent%20of%20African%20Americans.
[15] https://www.genome.gov/news/news-release/genetic-carriers-sickle-cell-disease-higher-risks-blood-clots-across-diverse-ancestries