

**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 2027 Funding for the National Institutes of Health, Department of Health and
Human Services**

April 15, 2026

As the leading global organization for professionals in human genetics and genomics, the American Society of Human Genetics (ASHG) is grateful to the Subcommittee for its sustained leadership in promoting biomedical research through robust support for the National Institutes of Health (NIH). We appreciate the opportunity to submit testimony that highlights the groundbreaking advances in lifesaving treatments, therapeutics, and cures made possible by sustained bipartisan investment in the nation's biomedical research enterprise. ASHG represents over 8,000 scientists, clinicians, and educators dedicated to advancing human genetics and genomics to improve human health. Now more than ever, it is imperative for the United States to continue to invest in biomedical research and scientific innovation in order to maintain our leadership on the global stage. Sustained, predictable growth in NIH funding is essential to keeping pace with scientific advances and ensuring that researchers across the country can continue to drive lifesaving discoveries.

ASHG joins the Ad Hoc Group for Medical Research, as a coalition of biomedical research organizations, in recommending the appropriation of \$51.303 billion for NIH, a \$4.087 billion (8.7%) increase over the fiscal year (FY) 2026 enacted funding level. ASHG also supports the coalition's request of \$1.7 billion for the Advanced Research Projects Agency for Health (ARPA-H) to enable meaningful growth, accelerate progress toward improving the nation's health, and ensure that momentum in ongoing research is not lost. 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 F&A funding is essential to maintaining the infrastructure that makes biomedical research possible, including laboratories, data systems, compliance frameworks, and research support staff.

NIH Investments Lead to Breakthroughs in Human Genetics and Genomics Research

Over the past year, groundbreaking advances made by the human genetics and genomics research community have created hope for patients and families across the nation. In May, the United States celebrated the story of Baby KJ, an infant born with a rare and often fatal genetic disorder, who became the first person to be successfully treated using a CRISPR-based gene editing therapy. ASHG members worked as part of a multidisciplinary team to safely develop and administer the personalized treatment that has allowed Baby KJ to grow and thrive, highlighting the promise of gene editing technologies in treating individuals with rare diseases.

¹<https://grants.nih.gov/grants/guide/notice-files/NOT-OD-24-110.html>

The investment by NIH in the fundamental research that laid the groundwork for this revolutionary treatment, as well as the support provided for the scientists who came together at a critical moment to save Baby KJ, simply must continue.²

Moreover, human genetics and genomics research has contributed to remarkable progress in diagnostics and genome editing. For example, groundbreaking work by the Human Pangenome and Telomere-to-Telomere (T2T) consortia has produced the first near-complete human genome reference. This work is powering next-generation long-read sequencing technologies that significantly improve the detection of disease-causing variants—boosting diagnostic rates in previously unsolved cases and finally giving families hope. As rare diseases affect an estimated 400 million people worldwide, including 30 million in the United States, these advances are already improving the accuracy of diagnosis and enabling treatments for desperate patients who previously had none.³ Continued NIH support is critical to expanding access to these innovations, reducing health disparities, and moving toward a future where comprehensive genomic testing is widely available across all health care settings.

Other critical programs such as the *All of Us* Research Program, supported by the NIH, have successfully amassed genomic data from over 400,000 participants from across the United States, identifying over 275 million previously unreported genetic variants, as well as genetic variants that are robustly associated with 117 different diseases.⁴ Data from *All of Us* is already improving diagnoses, prevention, and treatments, and its continued data collection will drive future breakthroughs in understanding human genetics and improving public health for all Americans. Additionally, the Undiagnosed Disease Network (UDN), supported by the National Institute of Neurological Disorders and Stroke (NINDS), has also made substantial strides in our understanding of the human genome, 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 for others affected by rare diseases, and provide insights into the mechanism of common diseases.

These advances are only possible due to our strong federal investment in human genetics and genomics. 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 that will impact human health.

Human Genetics and Genomics Research Generates Significant Returns on Investment

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 year.⁷ Federal funding for human genetics and genomics research also leads to a tremendous return on investment, with the U.S. government receiving

² <https://www.nih.gov/news-events/news-releases/infant-rare-incurable-disease-first-successfully-receive-personalized-gene-therapy-treatment>

³ Steyaert, W. et al. Unraveling undiagnosed rare disease cases by HiFi long-read genome sequencing. *Genome Res* 35, 755–768 (2025).

⁴ 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>

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 <https://www.ashg.org/wp-content/uploads/2021/05/ASHG-TEconomy-Impact-Report-Final.pdf>

more than \$4.75 for each \$1.00 invested. Researchers in every state and nearly every congressional district benefit from NIH funding, which, in turn, fosters job creation and enables training of the next generation, ultimately supporting a robust and thriving economy.⁸ NIH-funded research has also spurred the development of genetic technologies, diagnostic tools, and precision medicine initiatives, leading to significant growth in the biotechnology, healthcare, and data science industries. Discoveries arising from NIH-funded research provide a vital foundation for the U.S. biomedical industry, which contributes over \$69 billion to the U.S. GDP each year and supports over 7 million jobs.⁹ 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 doubles accuracy, significantly outperforming previous tools. 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.¹⁰

Protecting Merit-Based Peer Review

ASHG strongly supports NIH's long-standing commitment to merit-based, peer-reviewed grant funding. This system remains the global gold standard for identifying the most promising, innovative, and impactful science. Maintaining the integrity and independence of peer review is critical to ensuring that federal investments are guided by scientific excellence and public health need. Any erosion of this process risks undermining confidence in federally funded research and could deter talented scientists from pursuing careers in biomedical research.

Each year, NIH evaluates roughly 80,000–90,000 grant applications through independent panels of more than 11,000 expert scientists, using a standardized scoring system to assess scientific impact, innovation, and feasibility.¹¹ Only about 15–25 percent of applications receive funding, reflecting the highly competitive nature of the process.¹² This two-tiered system—combining scientific peer review with advisory council oversight—ensures that funding decisions are grounded in scientific excellence while aligned with national health priorities. Further, the merit-based peer review system operates at less than one percent of the NIH budget, preserving funds for scientific discovery.¹³

Research Training Pipeline and U.S. Scientific Competitiveness

For decades, bipartisan support from Congress has positioned the United States as a global leader in biomedical research. Maintaining this leadership will require sustained and increased investment in the scientific workforce and research infrastructure, as countries such as China and the United Kingdom are rapidly expanding their investments in genomics and precision medicine, intensifying global competition and challenging the United States' historic edge in this field. Robust investment in NIH is critical to ensuring the long-term stability and success of the biomedical and research workforce, and there is no better way to do this than by supporting early career researchers, who are becoming increasingly vulnerable to funding

⁸ <https://www.faseb.org/science-policy-and-advocacy/federal-funding-data>

⁹ United for Medical Research. *Profiles of Prosperity: How NIH-Supported Research Is Fueling Private Sector Growth and Innovation*. 2013. http://www.unitedformedicalresearch.com/wp-content/uploads/2013/07/UMR_ProspersityReport_071913a.pdf

¹⁰ 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).

¹¹ NIH Center for Scientific Review 2022-2027 STRATEGIC PLAN
<https://public.csr.nih.gov/sites/default/files/2022-09/CSR-strategic-plan.pdf>

¹² *Science* 2015, DOI: 10.1126/science.aaa0185; NIH

¹³ <https://www.nih.gov/news-events/nih-news-publications/nih-record-ceases-publication>

instability. To address this, ASHG emphasizes the importance of sustained support for early-stage investigator (ESI) funding mechanisms, continued investment in training and career development programs, and policies that ensure equitable access to funding opportunities across career stages.

Another key factor threatening the research training pipeline is the increased use of multi-year awards, also known as forward funding, in NIH's grant-making process. While NIH has historically paid out most grants one year at a time, with only 5-15% of NIH grants using forward funding in FY 2024, that number rose to about 40% in FY 2025. Agency-wide, NIH awarded thousands fewer grants in FY25 than in FY24. If continued, greater reliance on forward funding would further reduce grant numbers, intensifying competition and limiting research output. Such a change will have an outsized effect on early-career researchers, decreasing their abilities to secure grants and risking them leaving research. ASHG appreciates the FY 2026 L-HHS bill language restricting the proportion of NIH grants that may be obligated for multi-year awards to FY25 levels; it is vital that the Subcommittee continue to limit forward funding at NIH to support early-career researchers and fund as many meritorious applications as possible.

Federal investment is foundational to the United States' biomedical workforce pipeline. NIH funding supports the training of PhD students, postdoctoral researchers, and clinician-scientists at universities and academic medical centers across the country, which serve as the primary training ground for the next generation of talent in biotechnology, pharmaceutical development, and the broader life sciences industry. Critically, this training function cannot be replicated by the private sector: biotechnology and pharmaceutical companies rely on hiring already highly trained scientists and are not structured to provide the long-term, exploratory, and resource-intensive training that NIH-funded academic environments make possible. Without sustained federal investment in NIH and early-career researchers, this pipeline will contract, if not collapse, limiting the ability of U.S. companies to compete globally, slowing the pace of medical innovation, and weakening one of the nation's most important economic and strategic advantages. Robust NIH funding and investment in early-career scientists is therefore not only a workforce issue, but also an economic and innovation imperative, as this funding supports hundreds of thousands of jobs nationwide, drives local economic activity, and fuels the pipeline of discoveries that lead to new diagnostics, therapies, and cures.

Summary

ASHG strongly urges the Subcommittee to appropriate \$51.303 billion for NIH's base budget in FY 2027 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 2027 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. ASHG stands ready to work with the Subcommittee to ensure that the United States continues to lead the world in biomedical discovery and innovation.

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.