



ASHG

**American Society of
Human Genetics**



ASHG's 2026 Advocacy Priorities

Federal investments in human genetics and genomics have transformed our understanding of human biology, from the Human Pangenome Reference Consortium to creating the foundation for breakthroughs in diagnostics and treatment options for cancer, Sickle cell disease, Alzheimer's disease, and countless other conditions. Federal funding is also powering the next era of precision medicine. Programs such as NIH's *All of Us* Research Program are enabling new discoveries in heart disease, behavioral health, liver disease, and many other conditions by providing data that better reflects the American population. NIH-supported newborn sequencing pilots, including BabySeq and BeginNGS, are exploring the medical, behavioral, and economic impacts of integrating genomic sequencing into the care of healthy and sick newborns. These programs aim to shorten diagnostic odysseys and help infants receive appropriate treatments as early as possible.

These investments are already changing lives. For example, Baby KJ, diagnosed with a rare genetic disorder, was successfully treated with a customized gene therapy. To ensure that researchers can continue pioneering discoveries like these, and that people of all ages can benefit from cutting-edge therapies, we advocate for:

A Robust Biomedical Research Enterprise

- **Medical and scientific progress relies on continued public investment in biomedical research, including fundamental, translational and clinical research.** Robust, predictable, and sustainable federal funding of research not only fuels the next generation of scientific advances but also creates a biomedical research enterprise that generates a breadth of scientific career paths and powers local, state, and national economies. We recognize the enormous value of public support for biomedical research and believe it is imperative that taxpayer dollars are spent judiciously.
- **Maintaining competitiveness across the global stage** to ensure that the United States is at the forefront of human genetics and genomics research discoveries and health care innovation and remains the preeminent destination for individuals seeking research training and careers, life-saving treatments, and therapeutics.
- **Promote positive initiatives in support of biomedical research**, including trust in science, bipartisan engagement, and addressing misinformation.



Funding for Rigorous Genetics and Genomics Research

- **Bolstering support for the National Institutes of Health (NIH)**, which funds life-saving biomedical research and drives our understanding of disease, prevention, and overall human health, as well as the Advanced Research Projects Agency for Health (ARPA-H), the National Science Foundation (NSF), and the Congressionally Directed Medical Research Programs (CDMRP), which also support human genetics and genomics within its research portfolio.
- **Establishing stable and robust funding mechanisms** that support human genetics and genomics research and train emerging scientists.
- **Maximize the number of awards funded by the NIH** by reducing administrative processes and procedures that delay or reduce the number of grants awarded each year.

Ethical and Responsible Applications of Genetics and Genomics Research

- **Promoting the ethical and secure use of artificial intelligence and machine learning (AI/ML) technologies** in human genetics and genomics research to drive innovation and mitigate risks to decision-making, diagnostics, patient data privacy, or reinforcing existing gaps in treatment and access.
- **Continuing to monitor potential biosecurity risks of human genetics and genomics data** and work with our global partners to develop best practices and implement coordinated strategies to mitigate emerging threats.
- **Establishing data sharing policies that can accelerate scientific discoveries** by allowing researchers to leverage existing deidentified data that can be built upon.
- **Protecting the genetic privacy and confidentiality of research participants** to establish the research community as trustworthy partners and prevent the misuse of genetic information.

National data repositories enable scientists to share research findings with the scientific community to foster collaboration, reduce waste, and increase transparency with the public.

Examples include:

- ▶ **Million Veterans Program:**
<https://www.mvvp.va.gov/pwa/>
- ▶ **Genomic Data Commons:**
<https://gdc.cancer.gov/about-gdc>

- **Supporting the translation of genetic and genomic research into medical and public health solutions** to ensure that the fundamental research supported by taxpayers can lead to life-saving therapeutics and technologies that are accessible to all.
- **Considering the ethical implications of gene editing and gene therapies** to guarantee that the benefits of these therapeutics for patients with rare or life-threatening diseases justify their use.
- **Opposing the patenting of human genes**, which would increase the costs of and reduce access to genetic testing, as well as stymie genetics research and the development of novel medical applications.
- **Emphasizing the rapid growth of new scientific knowledge in the regulation of Laboratory-Developed Tests (LDTs) and Direct-to Consumer (DTC) genetic testing**, balancing the need to rapidly deliver benefits to patients while providing trustworthy and high-quality health information.
- **Affirming reproductive freedom**, particularly with respect to known or presumed genetic characteristics of a fetus.



Patient and Family Stories

A Physician/Father's Perspective on the Potential of Genetic Research

"My son, Andrew, was born with an ultra-rare disease that leads to hundreds of daily seizures, developmental arrest and a laundry list of symptoms impacting most organ systems...One of the main benefits of participating in research is that it gives us a sense of purpose instead of feeling powerless. We have made tremendous strides for our families by breaking down silos and getting our scientific collaborators to work together virtually, sharing pre-print data and insights to minimize duplicative work and accelerate the pace of discovery."

► **Read the full conversation here:**
<https://www.ashg.org/advocacy/a-physician-fathers-perspective-on-the-potential-of-genetic-research/>

Strengthening the Scientific and Clinical Workforce and Expanding Participation in Research

- **Broadening participation across research cohorts** to promote access to personalized treatments for individuals from all genetic backgrounds.
- **Opposing discrimination against patients and research participants** based on their genetic information.
- **Encouraging public engagement in federally funded human genetics and genomics research** to ensure that all Americans can understand and thereby reap the benefits of the groundbreaking therapeutics and technologies supported by taxpayer dollars.
- **Empowering the research community** by establishing a strong workforce pipeline for junior investigators and postdoctoral researchers and promoting careers in the field of human genetics and genomics.
- **Developing strategies to leverage the transformative power of AI** and expand efforts to cultivate a multidisciplinary workforce of the future that can responsibly apply evolving technologies.
- **Supporting human genetics and genomics research that can improve health outcomes** influenced by social determinants of health, including access to care, geographic location, health literacy, and other socioeconomic conditions.

Visit this website to see the impact of federally funded research in your state:

► **Federal Research Funding Data**

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



How NIH-Supported Research Solves Mysteries

“I found my way to the Undiagnosed Diseases Network [UDN] in 2020 at the age of 42...Finally, I had answers...after 42 years of searching...It wasn't until I was finally able to reach out to a community of people who have [Charcot-Marie-Tooth disease] that it really dawned on me what a diagnosis meant. It means access to information, community and understanding that had long been closed off to me... Within weeks, my health and comfort had markedly improved just because of the knowledge gained from peers that I finally had access to **because of the hard work of the UDN.**”

► **Read the full interview here:**
<https://www.ashg.org/advocacy/a-patient-participants-perspective-on-the-potential-of-human-genetics-genomics-research/>



By advocating for these priorities, we strive to ensure that people everywhere realize the benefits of human genetics and genomics research.

ASHG partners with national and biomedical research organizations and coalitions to coordinate common, broad responses to major issues facing the research enterprise, such as overall funding and support for science. These organizations include Research!America, the Coalition for the Life Sciences, and the Federation of American Societies for Experimental Biology (FASEB).

Learn more about ASHG's advocacy work:



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