ASHG
American Society of Human Genetics

ASHG's 2025 Advocacy Priorities

Federal investments in genomics research have allowed scientists to map and sequence the human genome, which led to the invention of groundbreaking diagnostics and therapeutics for individuals with a wide array of diseases such as cancer, diabetes, and Alzheimer's, among many others. From the first pass at sequencing the human genome in 2003 to the Human Pangenome Reference Consortium, which aims to capture the entirety of human genetic variation, and the work done by the Telomere to Telomere (T2T) consortium to generate the first complete, gapless sequence of a human genome in 2022, federal funding is vital to provide new insights into the role of different sections of the genome.

In addition, other federally funded programs are allowing researchers and clinicians to pursue, develop, and disseminate precision therapies that can be used to treat patients with even the rarest diseases. To ensure that the scientific community can continue to advance groundbreaking research and patients can continue to benefit from lifesaving therapeutics, we advocate for:

A Robust Biomedical Research Enterprise

- **Scientific progress relies on continued public investment in biomedical research, including fundamental, translational and clinical research.** Robust, predictable, sustainable federal funding of research not only fuels the next generation of scientific advances, but also creates a biomedical research enterprise that generates a range of different 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.
- **Promote positive initiatives in support of biomedical research,** including the reestablishment of 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 **Department of Defense (DOD)**, which also supports human genetics and genomics within their research portfolio.
- **Establishing robust funding mechanisms** that support human genetics and genomics research and training.

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

Ethical and Responsible Applications of Genetics and Genomics Research

- **Promoting the ethical use and biosecurity of artificial intelligence and machine learning (AI/ML) technologies** in human genetics and genomics research to optimize their use and mitigate risks to decision-making, diagnostics, and patient data privacy.
- **Establishing data sharing policies that can accelerate scientific discoveries** by allowing researchers to leverage existing data that can be built upon.

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

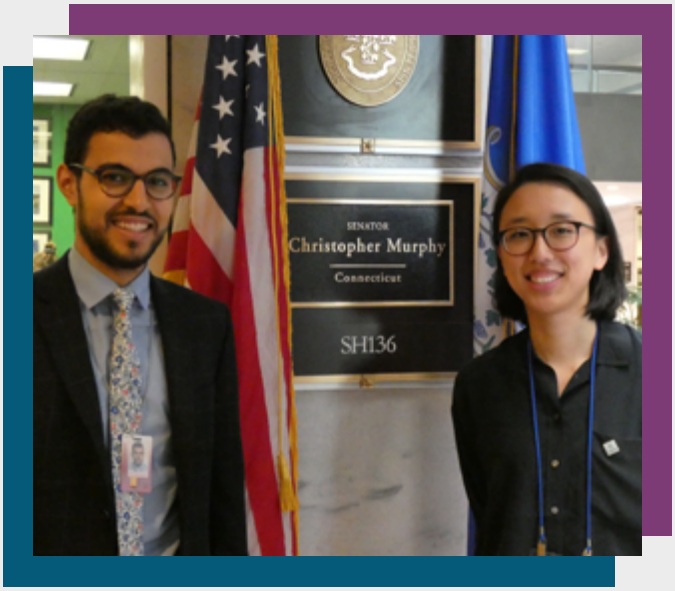
Examples include:

▶ Million Veterans Program:
https://www.mvp.va.gov/pwa/

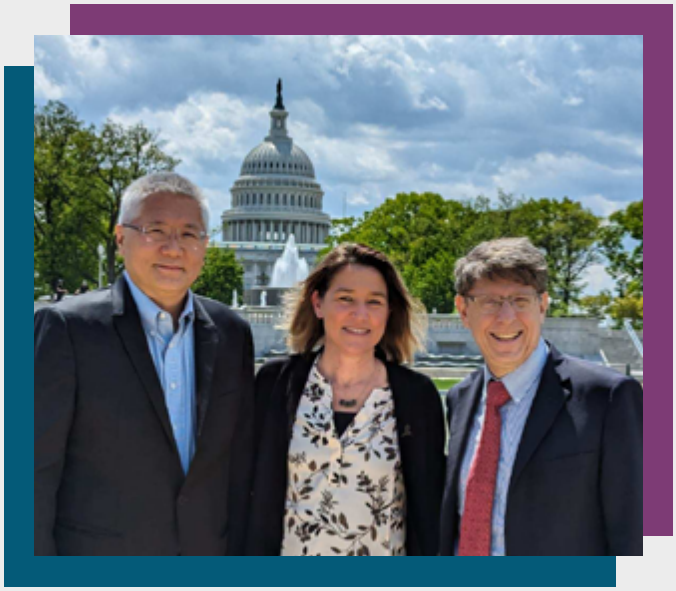
▶ Genomic Data Commons:
https://gdc.cancer.gov/about-gdc

- **Protecting the genetic privacy and confidentiality of research participants** to build trust between the public and the research community and prevent the misuse of genetic information by bad actors.

- **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.**



- **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.



- **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.

- **Recognizing the role of human genetics and genomics research in advancing U.S. competitiveness in biotechnology** while addressing potential national security concerns.

- **Emphasizing the integration 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/a-physician-fathers-perspective

Supporting the Scientific Workforce and Research Cohorts

- **Broadening participation across research cohorts** to promote access to personalized treatments for individuals with various 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 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.
- **Supporting human genetics and genomics research that can mitigate existing health disparities** exacerbated by social determinants of health including access to care, geographic location, health literacy, and other socioeconomic conditions.

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/A-Patient-Participants-Perspective

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 biomedical research, 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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