



ADVOCATE UPDATE

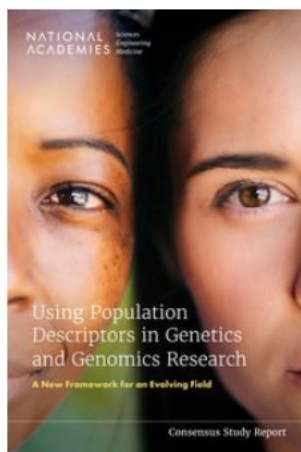
March 2023

ASHG Urges NIH Funding Increases in Congressional Testimony on FY24 Appropriations



On March 23, ASHG 2023 President Brendan Lee, MD, PhD, [submitted](#) outside witness testimony on behalf of ASHG to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies in support of FY 2024 funding increases for the NIH. ASHG urged the Subcommittee to appropriate \$51 billion (+\$3.5 billion over FY 2023) for NIH's base budget in FY 2024. In addition, ASHG shared how continued investment in NIH's foundational human genetics and genomics research has led to advances that resulted in novel therapies for both rare and common genetic diseases and conditions; communicated the imperative that participation in human genetics and genomics research reflect humanity's diversity; and asked the Subcommittee to recognize the privacy protections already established by Congress and NIH for genomic research data, and to ensure that broad data-sharing can continue to fuel scientific progress and maintain the United States' leadership and global competitiveness. The recording of the Public Witness Day is available [here](#).

NASEM Releases Report on the Use of Population Descriptors in Genomics Research



On March 17, the National Academies of Sciences, Engineering, and Medicine (NASEM) held a [webinar](#) discussing a new report, [Using Population Descriptors in Genetics and Genomics Research: A New Framework for an Evolving Field](#). An overall theme from the report is for researchers who utilize genetic and genomic data to rethink and justify how and why they use race, ethnicity, and ancestry labels in their work. ASHG has been deeply [engaged](#) in the proceedings of this committee; Charles Rotimi, PhD, ASHG 2022 President, represented the Society during the committee's public workshop in April 2022 where he communicated that greater diversity, equity, and inclusion in our research is a scientific and social imperative, that genetics affirms the singularity of the one *human* race, and that "race" and "ethnicity" labels should be avoided in human genetics and genomics research. Brendan Lee, MD, PhD, ASHG 2023 President, was recently [interviewed](#) about this NASEM report by *STAT News*. Dr. Lee applauded the report and said it was in line with the priorities of ASHG to diversify both the scientists conducting research and those being studied. He said the guidelines provided a framework to improve the quality of human genetic research and added that it would take time for scientists to incorporate some of the recommendations in their future work. "This is the very first step," he said. "It's not something that can be done in a day."

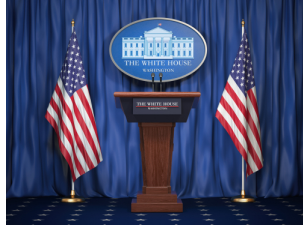
NIST Releases Report on Cybersecurity of Genomic Data



The National Cybersecurity Center of Excellence (NCCoE) at the National Institute of Standards and Technology (NIST) this month released their initial public report, [Cybersecurity of Genomic Data](#), which describes current practices in risk management, cybersecurity, and privacy management for protecting genomic data along with relevant challenges and concerns. It also notes possible areas for new laws and policy solutions, such as opportunities to expand the *U.S. Genetic Information Nondiscrimination Act (GINA)* to include life insurance, acceptance into the military, or senior residential communities. Critically, the report acknowledges that NIH continues to play a leading role in genomic research and the protection of genomic data, recognizes the value of data sharing for accelerating scientific advancements, and affirms the importance of meaningful informed consent and universal ethical standards in human genomics research.

Thematically, the report incorporates several points [shared](#) by ASHG 2021 President Gail Jarvik, MD, PhD, on behalf of ASHG during the NIST public workshop in 2022. The Society is pleased that its perspective was considered and is looking forward to other's continued work on this topic.

President's FY24 Budget Request Released



The White House [released](#) its FY 2024 budget request on March 9 along with a summary [fact sheet](#). This release launches the annual appropriations process once again as Congress begins to develop its own FY 2024 budget allocations. The president is proposing \$48.265 billion for NIH's base in FY 2024, which would represent an \$811 million (+1.7%) increase over the comparable FY 2023 funding level. Additionally, the proposal requests \$2.5 billion for the Advanced Research Projects Agency for Health (ARPA-H), which would represent a \$1 billion (+66.7%) increase over FY 2023. ASHG advocacy coalition partners added our collective voices on the President's budget: the Ad Hoc Group for Medical Research issued a [press statement](#) in response to the president's budget request on March 10 and Research!America released a [budget chart](#) outlining how the FY 2024 numbers measure up compared to previous years. If you'd like to read more about the congressional appropriations process, the Congressional Research Service (CRS) has a useful [primer](#).

In Other News

- As part of the united NIH advocacy community, ASHG has joined the nearly 400 stakeholders who signed on to the Ad Hoc Group for Medical Research's FY 2024 [community letter](#) to Congressional appropriation leaders proposing at least \$51 billion for NIH, a \$3.5 billion increase over the FY 2023 program level, which would allow NIH's base budget to keep pace with the biomedical research and development price index (BRDPI) and allow meaningful growth of 5%.
- The National Human Genome Research Institute (NHGRI)'s [Congressional Justification](#) (CJ) noted the continued funding partnership of ASHG's [Human Genetics Scholars Initiative](#).
- On March 15, Senate Majority Leader Chuck Schumer (D-NY) and Senator Todd Young (R-IN) [received](#) the *Edwin C. Whitehead Award for Medical Research Advocacy* from Research!America. These national leaders have demonstrated a commitment to making STEM and research funding national priorities, namely in garnering bipartisan support for the [CHIPS and Science Act of 2022](#).
- The American College of Medical Genetics & Genomics (ACMG) published a new [policy statement](#) in *Genetics in Medicine* on clinical applications of polygenic scores, complementing ASHG's recent [Guidance](#) on this topic. The ACMG's position is that preimplantation polygenic risk score testing is not yet appropriate for clinical use and should not be offered at this time.
- Yvette Seger, Director of Science Policy, Federation of American Societies for Experimental Biology (FASEB) gave a crash course with Research!America on how to weigh in on policy at NIH and other research agencies through Requests for Information (RFIs) (e.g., [this RFI](#) on NIH-supported postdoctoral training). [Watch](#) the recording and [view](#) the slides. ASHG supports FASEB as an affiliate member.
- Funding gaps for designated Principal Investigators from underrepresented groups are narrowing but have a long way to go to reach parity, according to analyses of FY2010-FY2022 funding rates for [NIH Research Project Grant \(RPG\) and R01-equivalent applicants](#) and mentored [career development \(K\) applicants](#). Increasing diversity in the scientific workforce remains a policy priority for ASHG and is a key part of our advocacy messaging to policymakers.

ASHG Calendar

- On April 12, Olivia Lee, BS, and Mitchell Machiela, ScD, MPH, will discuss their long-read sequencing investigation of the 6p25.1 Ewing sarcoma susceptibility locus. Register [here](#).
- Abstract submissions for ASHG 2023 [open](#) on April 19. The deadline is **June 8**.
- ASHG 2023 [registration](#) will open in May!

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