



American Society of Human Genetics

ADVOCATE UPDATE

May 2024

ASHG's 2024 Capitol Hill Meetings



ASHG advocates met with 15 congressional offices earlier this month to share their stories and the impact of human genetics research supported by the NIH at their institutions and across the country. Current and former trainee advocates from the [Advocacy Certificate for Human Genetics and Genomics Trainee](#) (ACGT) program joined members of the [Government and Public Advocacy Committee](#) (GPAC) to convey how human genetics research is transforming medicine and saving lives. Speaking of the importance of continued robust support for NIH, ASHG advocates called on their Legislators to support the [community ask of \\$51.3 billion](#) for NIH's base budget in Fiscal Year (FY) 2025. Advocates also spoke about key ASHG policy priorities including increasing diversity in the human genetics workforce and in research cohorts.

Take action by participating remotely in ASHG advocacy efforts by [using this pre-filled form](#) to email your Members of Congress in support of robust NIH funding for FY25.

Take Action

ASHG Shares Written Testimony with Congress in Support of NIH Funding



This month, Bruce Gelb, MD, 2024 ASHG President, submitted [outside witness testimony](#) (OWT) to the House and Senate Appropriations Subcommittees on Labor, Health and Human Services, Education, and Related Agencies (LHHS) on behalf of the Society. ASHG continues to join together with the broader research community in [calling for \\$51.3 billion](#) in funding for the NIH in FY25. In justifying this level of funding, Dr. Gelb shared extraordinary advances in human genetics and genomics research, including novel CRISPR-Cas-9-based gene therapies to treat sickle cell disease, the discovery of unprecedented insights into the biological causes of Alzheimer's disease, and the groundbreaking research into the

causes and treatments of rare and common diseases that are enabled by the NIH. In addition to asking for the crucial funding increases needed to support the advancement of human genetics and genomics research, the OWT also highlights key policy priorities including increasing diversity in research cohorts and the importance of broad data sharing for human genetics and genomics research.

Upcoming ASHG Webinar Series on Community Engagement in Genomics Research



The ASHG Professional Practice and Social Implications (PPSI) Committee is excited to host an ethical, legal, and social implications (ELSI) training virtual seminar series in June. The course, delivered through a 3-part webinar series entitled, "Towards Health Equity: Prioritizing Community Partnerships in Human Genetics Research" will continue and build on the conversations from the 2022 ASHG Guidance, [Addressing Underrepresentation in Genomics Research through Community Engagement](#), as well as conversations throughout the broader genetics and genomics community. The webinars will take place during three consecutive Thursdays from 12-1 pm ET starting on June 13, 2024. This course is open to both ASHG members and non-members and is geared towards individuals new to the topic, including trainees and early career researchers. To sign up or learn more about this program [click here](#) or use the button below.

Register

In Other News

- In May, nearly 200 Representatives and 56 Senators signed onto [Dear Colleague Letters](#) sent to leaderships of the House and Senate LHHS Subcommittees on Appropriations. These letters called for appropriators to "maintain a strong commitment" to the NIH in FY 2025.
- Curious to know the impact of federal research funding? [Learn how much NIH funding](#) went to your state and district with the Federation of American Societies for Experimental Biology (FASEB) fact sheets!
- NHGRI will host a two-day virtual workshop on May 28-29, 2024, to further explore the recommendations from the National Academies of Sciences, Engineering and Medicine (NAEM) 2023 report, *Using Population Descriptors in Genetics and Genomics Research: A New Framework for an Evolving Field*, with regards to legacy genomic data. [Click here](#) to learn more and register for the workshop.
- On May 9, U.S. Senator Bill Cassidy (R-LA), Ranking Member of the Senate Health, Education, Labor, and Pensions (HELP) Committee, released a [white paper](#) on the NIH and set forth proposals intended to maximize the effectiveness of current NIH funding.
- On May 1, the STEMM Opportunity Alliance (SOA), led by the American Association for the Advancement of Science (AAAS), announced a strategic plan to help 20 million people from historically excluded and marginalized communities enter, contribute to, and thrive in STEMM fields in the [STEMM Equity and Excellence 2050: A National Strategy for Progress and Prosperity](#).
- In case you missed it, [watch the recording](#) of the most recent ELSI Friday Forum, *Patients as Partners in Sickle Cell Disease Research in Africa: Ethos, Challenges and Lessons Learned*, hosted by ELSI Hub on May 10.
- ASHG will be participating in the Congressional Life Science Fair on June 10 held in the Rayburn House Office Building. At this annual event and reception, the biomedical

research community engages with Members of Congress and their staff via hands-on examples of how federal investment accelerates scientific progress and advances public health.

ASHG Calendar

- ASHG wants your research on ethical, legal, and social implications (ELSI) at the ASHG 2024 Annual Meeting! Don't miss your chance, [submit your abstract](#) by June 5 at 5 PM Eastern Time.
- Applications are now open for the 2024-2026 [Human Genetics Scholars Initiative](#) (HGSI) Program. [Learn more and apply](#) by the June 14, 2024 deadline.
- Mark your calendars for the [ASHG 2024 Annual Meeting](#), taking place in Denver, Colorado from November 5-9, 2024. Registration will open in mid-June!

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