



American Society of Human Genetics

ADVOCATE UPDATE

March 2024

Biden Administration Releases an Executive Order on Sensitive Data



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At the end of February, President Biden issued an [Executive Order](#) (EO) to prevent access to "bulk sensitive personal data or United States Government related data" by countries of concern. The EO notes that it is not intended to "impose measures aimed at a broader decoupling of the substantial consumer, economic, scientific, and trade relationships that the United States has with other countries." The EO directs the Attorney General and Department of Homeland Security to regulate the uses of sensitive data, including genomic and other 'omics data. ASHG [has been vocal](#) about [supporting research policies](#) that facilitate data sharing and protect the confidentiality of research participants' medical and genetic data in a way that both advances research and respects participants' preferences. The Society has long recognized the importance of international collaborations and the integral role that data sharing plays in advancing science and medicine. ASHG will continue to monitor the development of regulations and risk assessments and be ready to provide expert input as appropriate.

Meet the 2024 Cohort in the Advocacy Certificate for Human Genetics and Genomics Trainees Program!



In February, ASHG welcomed the 2024 cohort of trainees in the [Advocacy Certificate for Human Genetics and Genomics Trainees \(ACGT\) Program](#). To launch the third year of the program, advocates attended a virtual orientation and introductory webinar on policy and advocacy at ASHG. Joined by Marie Ternieden, interim ASHG CEO, and Tony Wynshaw-Boris, MD, PhD, Chair of the Government and Public Advocacy Committee, advocates heard how this program furthers ASHG's mission. Dr. Wynshaw-Boris explains, "The ACGT program is part of the Board-approved Action Plan and seeks to equip early-career ASHG members with the skills to engage with policymakers as well as grow ASHG member activity in advocacy. In these challenging times, it is critical that we build relationships with Congress, foster trust in science and ensure federal policies that

support research and robust NIH and National Science Foundation (NSF) funding. We hope the experience of the program will benefit the trainees throughout their career." To learn more about the ten newest ASHG members to participate in the program, visit the [ACGT Program Trainees page!](#)

Recording Available: Advancing Global Data Sharing and Complex Considerations Policy Forum Conversation



Source: ASHG 2023 Annual Meeting

This past November at the [ASHG 2023 Annual Meeting](#) in Washington, D.C. the ASHG Government and Public Advocacy Committee hosted a Policy Forum on [Advancing Global Data Sharing and Complex Considerations](#). A panel, made up of those with a range of expertise in genomic data sharing and moderated by Gail Jarvik, MD, PhD, 2021 ASHG President, shared important considerations and perspectives in thinking about global data sharing. The [recording](#) of this discussion is now available on the [ASHG Learning Center](#).

In Other News

- ASHG recently interviewed Lee H. Moultrie II, a participant in the [In Our DNA SC program](#). [Read his story](#) on the impact of the program in the most recent edition of [The Messenger](#).
- On March 11, President Biden released a [budget request for FY25 funding](#), requesting a total of \$48.3 billion for NIH, an \$871.5 million (+1.8 %) increase over the comparable FY 2023 funding level (FY24 funding for NIH has not been released at the time of writing).
- ASHG was one of approximately 400 organizations that [signed](#) a March 11, 2024 letter requesting Congressional leaders secure robust funding for research and set the NIH budget for FY25 at \$51.3 billion.
- Curious to know the impact of federal research funding? [Learn how much NIH funding](#) went to your state and district with the newly updated FASEB fact sheets!
- ASHG joined advocates from the [Genetic Society of America](#) at the [Coalition for the Life Sciences](#) Capitol Hill Day on March 5 to advocate for robust NIH and National Science Foundation research funding as Congress works to finish FY24 funding and begins work on funding for FY25.
- During Rare Disease Week at the end of February, ASHG attended events including a Legislative Conference and Hill Day hosted by the EveryLife Foundation for Rare Diseases and the NIH's Rare Disease Day. Check out ASHG's [advocacy fact sheet](#) on how human genetics delivers health advances in rare disease and how Congress can support research.
- On March 13, ASHG attended the [Research!America 2024 Advocacy Awards](#) in Washington, D.C. At the reception, Sen. Patty Murray (D-WA) and Sen. Bill Cassidy, MD, (R-LA) were each honored for their contributions to strengthening our nation's research capabilities and advancing medical progress with the Edwin C. Whitehead Award for Medical Research Advocacy.
- In case you missed it, [watch the recording](#) of the most recent ELSI Friday Forum, hosted by ELSI Hub on March 8 on [The Impact of Dobbs on Emerging Reproductive Technologies](#).

ASHG Calendar

- Watch the recordings of the recent ASHG webinars on the use of population descriptors: a webinar series on [Navigating the Use of Population Descriptors in](#)

[*Human Genetics and Genomics Research*](#) and a journal club, [*Tracing decision points in the use of race, ethnicity and genetic ancestry as population descriptors in genomics research*](#).

- Abstract submissions for the [ASHG 2024 Annual Meeting](#) in Denver, CO from November 5-9, 2024, will open at the end of April. Learn more [here!](#)

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