



American Society of Human Genetics

ADVOCATE UPDATE

July 2024

House Appropriations Committee includes NIH Restructuring Proposal in the FY25 Appropriations Bill



The House Appropriations Committee recently passed a budget proposal for Fiscal Year 2025 (FY25) that will advance out of committee. Unfortunately, the NIH funding in the bill amounts to a funding cut because it does not reach the estimated \$51.3 billion needed to keep pace with the rate of inflation. The [Labor, Health and Human Services, Education, and Related Agencies Appropriations \(L-HHS\) Bill](#) also includes a proposal to restructure the National Institutes of Health (NIH) and its 27 institutes and centers. The plan would combine NHGRI, NIGMS and NLM into a new "National Institute of General Medicine Sciences." ASHG does not support the proposed NIH framework or including such framework in the funding bill. The Society recently shared a [position statement](#) on this topic and, additionally, looks forward to responding to the recent request for stakeholder input from Energy and Commerce Committee Chair Cathy McMorris Rodgers (R-WA) on recommendations for NIH structural and policy reform. Please contact your legislators and let them know that you do not support the bill as presented.

Click on the "Take Action" button below to use the pre-filled ASHG email template and communicate the impacts of including policy to restructure the NIH in the FY25 L-HHS Bill.

Take Action

ASHG Calendar: Events and Important Dates

- The [ASHG 2024 Annual Meeting](#) will be in Denver, Colorado from November 5-9, 2024. [Register](#) before the ASHG 2024 Annual Meeting Early Bird Registration Deadline on Aug 21, 2024 at 5:00pm ET.

New ASHG Advocacy Resource, "6 Ways to be an Advocate"



Have you seen the updated "[6 Ways to be an ASHG Advocate](#)" guide? Learn how you can help be an effective advocate for human genetics and genomics research and related policies. From taking action by voting to staying informed on current policy and advocacy news, making your voice heard and engaging in advocacy can be incorporated into your day-to-day life! [Read more by clicking on this link.](#)

2024 Rally For Medical Research- Registration Open!



The 12th annual "Rally for Medical Research Hill Day" will take place on Thursday, September 19, 2024. During this event, advocates will meet with their congressional offices, urging our nation's policymakers to make funding for NIH a national priority and raising awareness about the importance of continued investment in medical research. ASHG sponsors this advocacy event to join with advocates from about 400 organizations and speak with one voice about making NIH funding a national priority. This year, ASHG will be participating with advocates in the 2024 Advocacy Certificate for Human Genetics and Genomics Trainees (ACGT) program. **Participants must register by September 4, 2024.** To learn more about the Rally for Medical Research, visit the [Rally website](#).

[Register](#)

In Case You Missed It: ASHG Webinar Series on Community Engagement



Last month, the ASHG [Professional Practice and Social Implications Committee \(PPSI\)](#) held a three-part webinar series on community engagement. This series continued conversations in the field on how to better implement community-based participatory practices into genetics and genomics research throughout the research lifecycle. During the series, speakers shared first-hand examples of how to take recommendations outlined in the [2022 ASHG Guidance, "Addressing Underrepresentation in Genomics Research through Community Engagement,"](#) and put them into practice. Register to access the resources and view the recordings of the presentations from this series by [using this link](#).

In Other Policy News

- ASHG joined other societies and members of the research community [to express concern about including NIH restructuring in the FY25 House L-HHS Appropriations Bill](#) without feedback from the research community.

- ASHG joined the research community in signing the [Coalition for Health Funding and NDD United letter](#) urging Congress to appropriate robust non-defense discretionary funding, which includes scientific and medical research.
- Representatives Diana DeGette (D-CO) and Larry Bucshon, MD (R-IN) have circulated a [letter](#) seeking input on key questions to inform "Cures 3.0," the latest iteration of the 21st Century Cures Act. Feedback should be submitted by August 2 to cures.rfi@mail.house.gov. ASHG looks forward to engaging with Congress on this topic.
- The NIH has an ongoing request for information on strategies to maximize public engagement in NIH-supported clinical research. See [here](#) for more information on how to submit a response before the August 14, 2024 deadline.
- In case you missed it, [watch the recording](#) of the most recent ELSI Friday Forum, "Global Models for Embedding ELSI Research: What does equitable integration mean?" hosted by ELSI Hub on July 12.
- On July 17-18, ASHG attended a [public workshop](#) organized by the Roundtable on Genomics and Precision Health of the National Academies of Sciences, Engineering, and Medicine (NASEM). As part of the effort to improve the quality of genomics research by understanding where obstacles to sustained community involvement remain, discussions included opportunities for training, methods to measure success of partnerships, and how community engagement for genomics might differ when working with various underrepresented communities.
- Follow along with the FY25 appropriations process by using [this American Association for the Advancement of Science \(AAAS\) tool](#).
- Visit [this United for Medical Research \(UMR\) tool](#) to learn about the impact of NIH funding in your state and across the country!

The American Society of Human Genetics
6120 Executive Boulevard, Suite 500
Rockville, Maryland 20852

[Privacy Policy](#)