


American Society of Human Genetics
ADVOCATE UPDATE

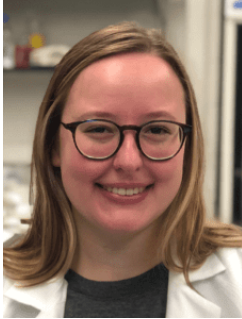
ASHG Heading to Capitol Hill (Virtually)



ASHG's Government & Public Advocacy Committee (GPAC), members of the ASHG Board, and trainees in the Advocacy Certificate for Human Genetics and Genomics Trainees (ACGT) program will be holding a second annual (virtual) Hill Day on May 11. Participants will advocate for robust funding for the National Institutes of Health (NIH), express their support for measures to diversify participation in human genetics research, and communicate the essential value of responsible broad data-sharing for human genetics & genomics research. For more reading material that supports ASHG's Hill Day messages, these fact sheets highlight how [consent and privacy are important for human genetics research](#), the [importance of participant diversity in genetics and genomics research studies](#), and the [positive impacts for the economy](#) that are derived from modern human genetics and genomics science. Watch ASHG's social media channels for alerts and updates on Hill Day priorities and ways to get involved.

Trainee Members Can Get Involved in Advocacy Too!

There are also opportunities for ASHG trainee members to get involved in advocacy outside of designated Hill Day events. In the [March Advocate](#)



[Update](#), ASHG/NHGRI's 2021-2022 Genetics & Public Policy Fellow, Nichole Holm, PhD, shared how her position allows her to use scientific skills beyond the bench to help the public. One of the trainee advocates in ASHG's [ACGT Program](#), Christina Del Greco (pictured), [shared her perspective](#) about the importance of advocacy and how to get involved in ASHG's [Nascent Transcript](#) newsletter. Look for more perspectives on engagement and advocacy in future Advocate Updates!

ASHG President Speaks at NASEM's Workshop on Population Descriptors



The National Academies of Sciences, Engineering, and Medicine (NASEM)'s Committee on Use of Race, Ethnicity, and Ancestry as Population Descriptors in Genomics Research held a public workshop on April 4 to review and assess the existing methodologies, benefits, and challenges in the use of race, ethnicity, and other population descriptors in genomics research, and to discuss how the use of population descriptors could be improved upon in the future. The 2022 ASHG President,

Charles Rotimi, PhD, said, "Greater diversity, equity, and inclusion in our research is a scientific and social imperative. Race and ethnicity are social constructs, and 'racial' and 'ethnic' categories are currently used as highly imperfect proxies for human genetic variation." [Read more at our blog](#). ASHG has also provided [written comments](#) on population descriptors to NASEM. The recording for the April 4 public workshop is [available here](#). The next public workshop for this committee will take place on June 14.

Washington Update: President's FY 2023 Budget Request

In late March, President Biden released the fiscal year (FY) [2023 budget request](#), which includes \$49.2 billion in total for the National Institutes of Health (NIH), \$4 billion of which is specifically directed to the new Advanced Research Projects Agency for Health (ARPA-H). This



proposed budget allocates \$45.3 billion for the NIH base budget, a \$275 million increase (+0.6%) over FY 2022, and includes cuts for institutes that fund human genome research. ASHG is joining the research community in asking that Congress provide at least \$49 billion for NIH baseline funding in FY23 (+7% over FY22), and ARPA-H funding that supplements, but does not supplant, investments in NIH's core research.

Advocacy Alert: Access to Genetic Counselor Services Act



ASHG, in close alliance with the National Society of Genetic Counselors (NSGC), supports the Access to Genetic Counselor Services Act (H.R. 2144/S. 1450). Congress can improve access to genetic counselors by enacting H.R. 2144/S. 1450, which would allow Centers for Medicare and Medicaid Services (CMS) to directly reimburse genetic counselors for the genetic counseling services they provided to Medicare beneficiaries.

Contact your representatives and senators via e-mail using the link below, highlighting the importance of timely action to improve access to genetic counseling services and benefit public healthcare.

[Improve Access to Genetic Counselors](#)

In Other News

- The deadline to submit an application for the [ASHG Genetics & Public Policy Fellowship](#) has been extended to April 25, 2022.
- The [Human Genetics Scholars Initiative](#) was highlighted in NHGRI's [FY 2023 Congressional Justification](#). Applications for the 2022-24 program will open in late April.
- Ned Sharpless, M.D., the director of the National Cancer Institute (NCI) since 2017, [announced](#) that he has decided to step down at the end of April. NCI Principal Deputy Director Douglas R. Lowy, M.D., will serve as NCI's acting director effective April 30, 2022.

- ARPA-H will be [housed within the NIH](#); however, instead of reporting to the NIH director, the new leader will report directly to the HHS secretary. Where the new research agency will be physically located is still unclear, and many of the country's leading biomedical research hubs are candidates.
- The Science & Technology Committee (STAC) and *CQ Roll Call* held a webinar in late March to discuss the importance of investment in science and technology, methods to strengthen the STEM workforce, and Congressional actions to help keep the U.S. innovative and globally competitive. [Watch the recording here](#).
- In late March, Arizona State University, Baylor College of Medicine, and the Museum of Science, Boston [shared preliminary insights and results](#) gathered from national citizen deliberations around the ethics and governance of human genome editing (HGE).
- Pew Research [released the results](#) of a survey on public opinion of artificial intelligence and the use of human enhancement technologies, including [gene editing in embryos](#). Eighty percent of those surveyed expressed concern over current safety standards and thought that *"the testing regime for gene editing to greatly reduce a baby's risk of serious diseases should be higher than that currently applied to testing medical treatments."*
- The [5th ELSI Congress](#) on ethical, legal, and social implications of genetics research will be held from May 31 – June 3, 2022. Registration for this event is free and [available here](#).

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

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