



# ASHG

American Society of Human Genetics

## ADVOCATE UPDATE

### New ASHG *Guidance*: Community Engagement as an Approach to Addressing Underrepresentation in Genomics Research



Earlier this month, ASHG [published](#) a new professional *Guidance* in the *American Journal of Human Genetics* on community engagement as a strategy to address underrepresentation in genomics research. The *Guidance* provides genetics & genomics researchers with a starting point for building meaningful, trustworthy, and long-term working relationships with communities who are historically marginalized and underrepresented in genetics & genomics research. Recognizing that researchers do not

always have formal training on specific ethical or social implications, ASHG sees the creation of this *Guidance* as a tangible and constructive step in responsible application of research.

### ASHG Welcomes the 2022-2023 ASHG/NHGRI Genetics & Public Policy Fellow

In late August, Albert Hinman, PhD, joined as the new ASHG/NHGRI Genetics & Public Policy Fellow. This [fellowship](#), co-sponsored by the National Human Genome Research Institute (NHGRI), is designed for early-career professionals transitioning to a career in policy. [Learn more](#) about what brought Dr. Hinman to



science policy and why he thinks getting involved in policy and advocacy is an important part of being a scientist.

## ASHG Members Joined the Rally for Medical Research



September 14, 2022, marked the 10th anniversary of the [Rally for Medical Research](#). ASHG is proud to have again sponsored this event on Capitol Hill. The in-person event brought together over 250 participants from more than 30 states and DC who met with 190 congressional offices to advocate for robust and sustained increases to the NIH budget. This year, the research community is asking that Congress provide at least \$49 billion for the NIH base

budget, a \$4.1 billion increase for FY23, and urges House and Senate leadership to complete work on the FY23 spending bills as quickly as possible to avoid the delays and disruptions caused by continuing resolutions.

ASHG welcomed several trainee advocates from the Advocacy Certificate for Human Genetics and Genomics Trainees ([ACGT](#)) program who [shared](#) with members of Congress how investing in NIH improves health, drives economic activity, and saves lives.

## ASHG Interviews Dr. Debara Tucci in *The Messenger*



ASHG recently [interviewed](#) Debara Tucci, MD, MS, MBA, director of NIH's National Institute on Deafness and Other Communication Disorders (NIDCD), to learn more about the ongoing research projects at NIDCD in the fields of genetics & genomics and public health.

Read this and other exciting articles, including ASHG's [interview](#) with Sharon Terry, MA, President and CEO of Genetic Alliance, in the Fall edition of [The Messenger](#).

## In Other Policy & Advocacy News

- ASHG is working actively to incorporate language in the FY23 Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS-ED) spending bill that would support greater inclusion of historically marginalized communities in genomics research. The efforts would authorize a new community engagement program built on the success of the Community Engagement Alliance (CEAL) Against COVID-19 program that engaged underserved populations in COVID-19 research. The Society is pleased that the new program is currently included in the [report](#) (pg. 132) accompanying the Senate's draft appropriations bill. ASHG will work to maintain this language in the final spending package and secure future funding for the program.
- Sen. Thom Tillis (R-NC) recently introduced the [Patent Eligibility Restoration Act of 2022](#). The text of the bill states that "a human gene that is isolated, purified, enriched, or otherwise altered by human activity...shall not be considered to be unmodified," and is therefore eligible to be patented. ASHG, in partnership with the Association for Molecular Pathology (AMP) and others, [opposes](#) gene patenting. With midterm elections coming up and the current session of Congress set to end in Jan., Sen. Tillis will likely have to resubmit the bill in the next Congress.
- Lawmakers returned to Washington this month where they will [need to pass a stopgap spending bill](#) to avoid a partial government shutdown on Oct. 1. House Democratic leaders are working on a tentative plan to consider a continuing resolution expected to extend FY22 government funding levels through Dec. 16. ASHG [has signed on](#) to Research!America's letter urging Appropriations leaders to complete action on FY23 appropriations without further delay.
- On Oct. 6-7, the National Human Genome Research Institute (NHGRI) and the University at Buffalo Center for Disability Studies will hold a [two-day symposium](#) entitled, "Irreducible Subjects: Disability and Genomics in the Past, Present and Future." The symposium will address historical and present-day constructions of disability and ableism, with a focus on the history and lived experiences of people with disabilities in the context of genetics and genomics.
- On Oct. 12, the National Academies of Sciences, Engineering, and Medicine (NASEM) Roundtable on Genomics and Precision Health is holding a [public workshop](#) entitled, "Realizing the Potential of Genomics across the Continuum of Precision Health Care: A Workshop."
- On Sept. 12, President Biden [announced](#) his intent to appoint Renee Wegrzyn, PhD, as the first director of the Advanced Research Projects Agency for Health (ARPA-H).
- Effective Dec. 2022, Anthony Fauci, MD, director of the National Institute of Allergy and Infectious Diseases (NIAID), will step down from his role in government service. He will also step down from his role as Chief Medical Advisor to President Biden. Lawrence Tabak, DDS, PhD, acting NIH director wrote a [statement](#) on Dr. Fauci's contributions and legacy.
- The White House Office of Science and Technology Policy (OSTP) [released](#) a [memorandum](#) to require federally funded peer-reviewed research be free to access without a 12-month

embargo. Publishing and data sharing costs will also be allowable in research grants. Federal agencies must update their public access policies as soon as possible, and no later than Dec. 31, 2025. [STAT News has more.](#)

## ASHG Calendar

- ASHG's [annual meeting](#) is October 25-29 in Los Angeles, CA. Already registered? Begin building your ASHG 2022 schedule with the [online planner](#) & [visit the registration resource center](#) to add ticketed events to your registration.
- On Sept. 14, ASHG [hosted](#) a virtual forum featuring a brief presentation of the "Facing Our History – Building an Equitable Future" initiative, a panel discussion, and dialogue. ASHG's DEI Task Force Chair Neil Hanchard, MBBS, D.Phil, discussed the initiative in a [recent article](#) for the fall edition of [The Messenger](#) newsletter. A recording of the report will be made available.

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