



American Society of Human Genetics

ADVOCATE UPDATE

## Joint Statement Against SCOTUS Decision to Roll Back Reproductive Rights



ASHG [released](#) a joint statement last month with the American College of Medical Genetics and Genomics (ACMG) and the National Society of Genetic Counselors (NSGC) expressing deep concern with the recent Supreme Court decision to overrule *Roe v. Wade*.

*“As genetics and genomics medical and research organizations, we affirm our belief that all pregnant people deserve care, including access to abortion, based on scientific and clinical evidence and their personal choices...[ACMG](#), [ASHG](#), and [NSGC](#) oppose laws that prevent families from using genetic information to inform reproductive choices, or that seek to prevent or criminalize healthcare professionals who inform patients of scientific knowledge or reproductive options.”*

## The Rally for Medical Research Hill Day is Back In-person on Sept. 14!

10<sup>TH</sup> ANNIVERSARY • 2013-2022

RALLY FOR  
**MEDICAL  
RESEARCH**<sup>™</sup>



ASHG is proud to again sponsor the [Rally for Medical Research](#). 2022 marks the 10th Annual Rally for Medical Research Hill Day, which will take place **in-person** in Washington, D.C. on **Wednesday, September 14, 2022**.

This is an event where researchers, patients and industry unite on Capitol Hill to advocate

for robust, sustained, and predictable funding for the NIH. [Registration is open!](#) The deadline for [booking housing](#) at the discounted rate is **August 22, 2022**.

## Washington Update: APRA-H Organizational Structure Established; Intitial Leadership Positions Filled



The Biden administration and Congress have established the Advanced Research Projects Agency for Health (ARPA-H) to provide a mechanism for the federal government to support transformative high-risk, high-reward research to rapidly drive biomedical and health breakthroughs that cannot readily be accomplished through traditional pathways. In May, Department of Health and Human Services (HHS) Secretary Xavier Becerra [named](#)

Adam H. Russell, D. Phil., as the acting deputy director for ARPA-H, and issued a directive establishing its organizational structure. However, ARPA-H's location is yet to be settled. [Read more](#) at ASHG's blog post.

## VALID Act Advances Towards Full Senate Vote



The Senate HELP Committee voted last month to advance the Verifying Accurate Leading-edge IVCT Development (VALID) Act of 2022 as part of the [FDASLA Act of 2022](#) legislation to enable the Food and Drug Administration (FDA) to continue to collect fees from prescription drug, generic drug, biosimilar, and medical device developers. If passed into law, the VALID Act will establish the FDA oversight of laboratory-developed tests. The American College of Medical Genetics and Genomics (ACMG) is concerned about the

burdens the VALID Act will impose on clinical testing laboratories. More information on ACMG's advocacy on the VALID Act is available on their [website](#).

## In Other Policy & Advocacy News

- The Supreme Court of the United States (SCOTUS) decision in *Dobbs v. Jackson Women's Health* will have ripple effects across state-level policy in the coming months and years. See [this map](#) for abortion policy states are planning or have already implemented. On July 8, the White House [announced](#) a wide-ranging executive order aimed at protecting abortion rights.

- The Center for ELSI Resources and Analysis ([CERA](#)) is holding a [webinar](#) on Approaches to Ethical Deliberation in Precision Public Health on July 27, 2022, 7:00 PM - 8:00 PM EDT.
- If you missed past ELSI Friday Forum Seminars on the ethical, legal, and social implications (ELSI) of genetics and genomics research, such as the Impact of SCOTUS's Dobbs Decision on Prenatal Genomics Research and Practice, past recordings are available [here](#).
- The House Appropriations Committee [released](#) their Fiscal Year 2023 Labor-Health and Human Services-Education funding bill in late June. The bill provides a total of \$47.5 billion for NIH, an increase of \$2.5 billion above the FY 2022 enacted level. This bill also includes \$2.75 billion for the Advanced Research Projects Agency for Health (ARPA-H), an increase of \$1.75 billion.
- [AAAS](#) and [Research!America](#) released statements applauding President Biden's nomination of Arati Prabhakar, Ph.D., to serve as his science advisor and the director of the White House Office of Science and Technology Policy (OSTP). ASHG has signed on to the American Institute of Physics' letter to Sen. Maria Cantwell (D-WA) and Sen. Roger Wicker (R-MS) asking for prompt consideration of the OSTP nominee by the Senate.
- The World Health Organization (WHO) [Science Council](#) has [issued](#) its first report on accelerating access to genomics for global health. The report argues that it is not justifiable ethically or scientifically for less-resourced countries to gain access to genomics technologies long after rich countries. To promote the expanded use of genomics, the report's recommendations address four themes: advocacy, implementation, collaboration, and associated ethical, legal and social issues.

## ASHG Calendar

- ASHG's [annual meeting](#) is on October 25-29 in Los Angeles, CA. Early [registration](#) pricing is available before August 30, 2022.
- [ASHG Webinar – July 28 at 1 PM ET](#). AnVIL in the Classroom: Cloud-scale Educational Resources for Modern Genomics.

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