



American Society of Human Genetics

ADVOCATE UPDATE

Advancing ASHG's Policy Priorities

Advanced Research Projects Agency for Health (ARPA-H)
Listening Session

August 11, 12:00-1:15 p.m. ET

Advocates for Research on Genomics,
Biomedical Engineering and Imaging, and
Health Informatics, and Medical Libraries



National Institutes of Health & the White House Office of Science and Technology Policy

On August 11, ASHG President Gail Jarvik, MD, PhD, [provided comments](#) on behalf of the Society during an Advanced Research Projects Agency for Health (ARPA-H) [listening session](#) with NIH and the Office of Science and Technology Policy (OSTP) leaders. NIH and OSTP have organized a series of ARPA-H listening sessions to get

feedback from stakeholders within the biomedical research community. In her remarks, Dr. Jarvik urged NIH to consider “diversity, equity, and inclusion be at the core of ARPA-H’s mission, both with respect to its scientific priorities and its workforce.” She also emphasized the need for responsible global data sharing to advance science and health, while also protecting participant privacy.

ASHG also [provided comments](#) on draft legislation for the [Cures 2.0 Act](#). The bill would authorize the creation of ARPA-H and contains other provisions related to health care. In the letter to the bill sponsors, Reps. Diana DeGette (D-CO) and Fred Upton (R-MI), ASHG recommended that the bill includes efforts to increase diversity in research participants.

House Approves \$49.4 Billion for NIH

The House has passed funding bills that would set NIH’s budget at \$49.4 billion in Fiscal Year (FY)



2022. The \$6.5 billion increase over FY 2021 includes \$3 billion to establish ARPA-H. The Senate has yet to begin work on the equivalent appropriations bill and is currently in recess until mid-September. Congress will need to pass funding legislation or a temporary funding measure before the start of the new fiscal year, October 1, to

prevent government shutdown. Check out our latest [blog post](#) for more details.

Advocacy Opportunity: Rally for Medical Research



The [2021 Rally for Medical Research](#) will take place virtually on September 23. The Rally brings together hundreds of scientists, patients, clinicians, and others in the community to meet with their representatives in Congress to advocate for NIH funding and biomedical research. ASHG is a proud sponsor of this annual event and we encourage all ASHG Advocates to participate. The deadline to register is August 30.

In Other News

- NIH has released the [NIH-Wide Strategic Plan](#) for FY 2021-2025. The plan outlines NIH's priorities for the next few years. Among the themes, NIH acknowledged the importance of increasing diversity in the workforce and in research cohorts, and the current programs at NIH focusing on these issues.
- A recent [report](#) looks at the size of the genomics industry in the United Kingdom. The report aligns well with [ASHG's Economic and Functional Impact](#) report for the U.S. in analyzing the growth of genetics and genomics sector.