



American Society of Human Genetics

ADVOCATE UPDATE

House to Consider \$49.4 Billion for NIH



Last week, the House Appropriations Committee passed funding bills that would provide NIH with a budget of [\\$49.4 billion for Fiscal Year \(FY\) 2022](#), an increase of \$6.5 billion over FY 2021. \$3 billion of that increase would be allocated for President Biden's new proposed agency within the NIH, the Advanced Research Projects Agency for Health (ARPA-H). The Committee also acknowledged the NIH's efforts on diversity in the biomedical

workforce and research participants along with further recommendations to increase those efforts. The full House is expected to consider the bill in a package with other funding bills next week.

To learn more about ARPA-H from the leaders of the Office of Science and Technology Policy (OSTP) and NIH, watch the [Information Session on ARPA-H](#) and read their [commentary](#) in *Science*. OSTP has also released a [concept paper](#) and [fact sheet](#).

Proposed Funding Boost for NSF



The House Appropriations Committee also voted for [\\$9.63 billion for NSF](#), a \$1.15 billion increase over FY 2021. Last month, the [House passed the NSF for the Future Act](#) (H.R. 2225), authorizing budget increases for NSF over the next five years. This follows the passage of the U.S. Innovation and Competition Act (USICA) by the Senate that authorized funding increases for NSF within a broader bill addressing research and technology. Of note, USICA contains numerous provisions related

to research security that are absent in the House bills. In particular, ASHG has [expressed concern](#) over a USICA provision that would require the NIH to ensure that human genomic sequencing "is conducted in a manner that appropriately considers national security risks." The two chambers are expected to go to conference to resolve the differences over the various bills.

Draft Legislation for 21st Century Cures 2.0 Released



Reps. Diana Degette (D-CO) and Fred Upton (R-MI) have released a discussion [draft legislation](#) for the 21st Century Cures 2.0. The legislation would authorize the creation of ARPA-H and incorporate the Research Investment to Spark the Economy (RISE) Act, to provide relief funding for COVID-19 related disruptions to researchers. ASHG [supported the RISE Act](#) along with the broader scientific community and will continue to advocate

for recovery funding for researchers. Other provisions in the draft include expanding coverage for genetic testing for pediatric rare diseases, directing the National Academy of Medicine to study how genetic testing may improve health care, and increasing diversity in clinical trials.

In Other News

- ASHG has signed a [community statement](#) in support of the use of fetal tissue in research to advance scientific and medical progress.
- The World Health Organization (WHO) has released two reports outlining its [recommendations](#) and [governance framework](#) for human genome editing. The WHO report follows the International Commission on the Clinical Use of Human Germline Genome Editing's [report](#) released last year. ASHG hosted leaders from the WHO and the Commission at the 2019 Annual Meeting for early discussions on the reports. Check out the recording at [ASHG](#).
- The NIH has issued a [Request for Information](#) on Developing Consent Language for Future Use of Data and Biospecimens. The deadline to submit comments is September 29, 2021.
- Save the Date: 2021 Virtual Rally for Medical Research will take place on September 23, 2021. Register [here](#).

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