



# ASHG

American Society of Human Genetics  
ADVOCATE UPDATE

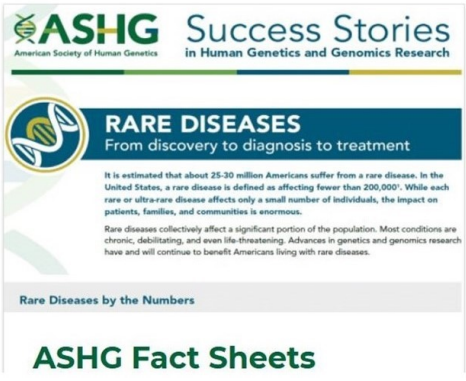
## NIH Budget Stays Flat Under Continuing Resolution



The NIH has been operating under a continuing resolution (CR) since the beginning of the Fiscal Year (FY) 2021 on October 1. The CR, which provides temporary funding to NIH and other federal agencies at current levels, will end on December 11. Check out [ASHG's latest blog post](#) for more information on the CR and stalled efforts by members of Congress to help the research

enterprise recover from the COVID-19 pandemic.

## Research!America Launches Vote Science Strong



**ASHG** Success Stories  
American Society of Human Genetics in Human Genetics and Genomics Research

**RARE DISEASES**  
From discovery to diagnosis to treatment

It is estimated that about 25-30 million Americans suffer from a rare disease. In the United States, a rare disease is defined as affecting fewer than 200,000. While each rare or ultra-rare disease affects only a small number of individuals, the impact on patients, families, and communities is enormous.

Rare diseases collectively affect a significant portion of the population. Most conditions are chronic, debilitating, and even life-threatening. Advances in genetics and genomics research have and will continue to benefit Americans living with rare diseases.

Rare Diseases by the Numbers

**ASHG Fact Sheets**

Research!America and partner organizations recently launched a non-partisan candidate engagement initiative ahead of Election Day. [Vote Science Strong](#) contains resources for the research community to engage with candidates on the importance of research funding, learn how to be a champion for science and information about voting.

The majority of Americans support science research

In the month before the election, a [timely poll](#) conducted by the Pew Research Center indicated that 82% of Americans believe that federal funding for science research is worthwhile. A similar finding by [ASHG in partnership with Research!America](#) found that a majority of Americans support increased federal funding for genetics research.

### Engage with elected officials and candidates

You can tell your representatives in Congress and candidates why funding research is important with this growing series of [ASHG fact sheets](#) on major advances in genetics and genomics research.

## Genetics Policy Forum and Networking Session



Friday, October 20, 2:20-3:30 p.m. ET.

Connect with other attendees interested in science policy and advocacy at the ASHG 2020 Virtual Annual Meeting! Chat with ASHG's [Government and Public Advocacy Committee](#) (GPAC) members and other leaders in the community about diversity in genomics, genetic privacy, genetic discrimination and many more topics. Meeting

registrants can register for the event [here](#).

## In Other News

- ASHG has signed onto a [multi-society letter](#) to the Office of Management and Budget opposing the elimination of federal training programs related to diversity, equity, and inclusion. The Society supports a diverse scientific workforce.
- Professional Practice and Social Implications (PPSI) Committee Co-chairs, Kyle Brothers, MD, PhD, and Sarah Tishkoff, PhD, are hosting a session at the AAAS 2021 Annual Meeting, February 8-11. The session is titled, "[Polygenic Risk Scores: Uses and Misuses in Health, Research, and Society](#)."
- The NIH will soon send out a [survey](#) to researchers on the impact of COVID-19 on extramural researchers.
- California Governor Gavin Newsom has [vetoed](#) a bill that would establish the Genetic Information Privacy Act which would require direct-to-consumer genetic testing companies to obtain express consent for collection and use of consumer's genetic data.
- Research!America is offering [civic engagement microgrants](#) (deadline November 9, 2020) for trainee science policy groups.