

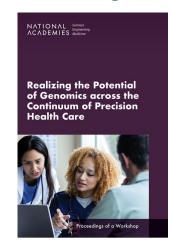
April 2023

ASHG Members to Communicate the Value of NIH Funding to Congress



ASHG will be holding virtual Hill meetings next month to urge Congress to support funding increases for NIH. For Fiscal Year (FY) 2024, ASHG is joining the research community in urging Congress to provide at least \$51 billion for NIH's base budget. This is a key time of year for advocacy efforts as Congress is deliberating on funding levels for federal agencies for FY 2024, and negotiations over raising the debt limit are threatening potential cuts to the federal budget back to FY 2022 levels. Watch for an action alert on **May 11** for more information on how you can contact your members of Congress and join in supporting policies that impact the research community. Also, look for reflections on the Hill meetings from the 2023 <u>Advocacy Certificate for Human Genetics & Genomics Trainees</u> cohort in upcoming editions of the *Advocate Update*!

Realizing the Potential of Genomics in Precision Health Care: Proceedings of a Workshop



The National Academies Roundtable on Genomics and Precision Health hosted a public workshop that examined how genomic data are used in health care outside of clinical genetics (e.g., prenatal screening and testing, newborn screening, polygenic scores). Realizing the potential of genomics across the broader clinical care spectrum will require understanding and addressing a range of challenges, including equitable access. The proceedings of the workshop, summarizing content from the October 2022 discussion, were <u>recently published</u>. Recurrent themes from the discussion, summarized by Christa Martin, PhD (pg. 73), include opportunities for equitable adoption of genomics; greater support for integration of genetics into routine care; improved education and training of providers and the public; engagement of all stakeholders in realizing the potential of genomics in precision health care; and electronic health record-integrated clinical decision support tools. ASHG was one of many supporters of this work, and several leaders and members of ASHG were involved in these discussions.

NIH Testifies at House LHHS Budget & Oversight Hearing on FY24 Appropriations



On April 19, the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS-ED) held a budget and oversight hearing with public health agencies. Witnesses included (from left to right) acting Director of the NIH, Larry Tabak, DDS, PhD, Director of the Centers for Disease Control and Prevention, Rochelle Walensky, MD, MPH, and Assistant Secretary for Preparedness and Response, Dawn O'Connell. Dr. Tabak shared examples of how President Biden's request for \$48.265 billion for NIH's base budget in FY 2024 would fund on-going research projects, and shared the negative impact that cuts back to FY 2022 funding levels would have on the agency and its ability to fund medical research grants. ASHG submitted questions for the record (QFR) to gather additional information about NIH's efforts to expand community engagement programs specifically for human genetics & genomics research; seek elaboration on the role diversity in research cohorts plays in advancing our understanding of human health; and the steps NIH is taking to address the challenges and barriers to achieving greater diversity, equity, and inclusion in the biomedical research workforce, especially in the field of human genetics and genomics.

In Other News

- According to an April 19 Washington Post <u>article</u>, the White House reportedly plans to nominate Monica Bertagnolli, MD, a surgical oncologist who became director of the National Cancer Institute (NCI) last fall, to lead the NIH.
- On May 4 at 12 pm ET, join Research! America for a conversation with Ned Sharpless, MD, Director of the National Cancer Institute from 2017-2022 and Acting Commissioner of the US Food and Drug Administration in 2019. Dr. Sharpless will join health policy expert and commentator Susan Dentzer, in a conversation focused on the NIH. What does NIH do, how does it do it, and why? Register here.
- The next ELSI Friday Forum Seminar, *Value and Values in Payment for Gene Therapies*, will be held on May 12 at 12 pm ET. Register here.
- United for Medical Research released their <u>2023 Annual Economic Report</u> (FY 2022) detailing NIH's role is sustaining the U.S. economy. In FY 2022, the NIH awarded \$36.68 billion in extramural research funding to <u>researchers in all 50 states and the District of Columbia</u>.
- Research!America's 2023 Advocacy Awards program on March 15 featured two
 insightful panel discussions with <u>this year's honorees</u>: the first focused on science
 communication and the second on trust in science. You can watch and share the
 videos <u>here</u>.
- On April 26, the House <u>passed</u> (217-215) a bill to raise the debt limit into next year and cap non-defense discretionary spending (which includes research funding) for a decade. The Senate is unlikely to take up the bill, but advocacy is essential.
- The Senate Labor-HHS Appropriations Subcommittee has <u>tentatively scheduled</u> a
 hearing on the FY 2024 budget request for the NIH on May 4. The deadline to <u>submit</u>
 <u>outside witness testimony</u> for FY 2024 to the Senate Labor-HHS-Education
 Appropriations Subcommittee is May 18. ASHG <u>submitted</u> testimony to the House
 Labor-HHS Appropriations Subcommittee in March and plans to submit testimony to
 the Senate Appropriations Subcommittee next month.

ASHG Calendar

- Registration for ASHG 2023 will open on May 5.
- Abstract submissions for ASHG 2023 are now open! The deadline is June 8.
- On May 10, Ruizhi "Vince" Duan, MS, will discuss using family-based genomics and rare variant analyses to explore the developmental genomics of congenital limb malformations. Register here.
- This year, National DNA Day on April 25 marked the 20th anniversary of the <u>Human Genome Project</u>'s completion and the 70th anniversary of the <u>discovery of the DNA double helix</u>. You can find all ASHG celebrations on the <u>ASHG DNA Day Celebrations page</u>, including the announcement of the <u>DNA Day Essay Contest winners</u> and a new <u>fact sheet</u> on different career paths in genetics.
- 2023 is also ASHG's 75th anniversary! <u>Learn about</u> the Society's 75th anniversary celebrations and activities as we celebrate, "One Humanity, Many Genomes."

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