

#### January 2023

### ASHG Celebrates Genomics Community Engagement Program in FY 2023 Omnibus



ASHG communicates with policymakers to ensure that human genetics and genomics research embodies a vibrant, collaborative community that contributes to accessible and equitable health discoveries. Efforts to broaden participation in research by all people must begin with meaningful engagement with historically and currently underrepresented communities. To this goal, ASHG championed community engagement language that was included in the FY 2023 omnibus appropriations bill. This language urged the National Human Genome Research Institute (NHGRI), in consultation with the National Heart, Lung, and Blood Institute (NHLBI) and the National Institute on Minority Health and Health Disparities (NIMHD), to establish and coordinate a community engagement program modeled after the NIH <u>Community Engagement Alliance</u> (CEAL) Against COVID-19 Disparities. The new program aims to support efforts to increase the participation of individuals historically underrepresented and hesitant to participate in human genetics and genomics research. ASHG celebrates this advocacy success and is exploring future engagement opportunities to ensure its provisions advance human genetics and genomics research and do so in ways that incorporate ASHG's values of diversity, equity, and inclusion.

## ASHG Conveys to White House the Bioeconomy Benefits, Needs of Genetics Research



ASHG recently <u>responded</u> to a select number of questions in a Request for Information (RFI) from the White House Office of Science and Technology Policy (OSTP) on the National Biotechnology and Biomanufacturing Initiative. OSTP released this RFI to seek public input on how advances in biotechnology and biomanufacturing can help support a strong bioeconomy. The insights provided by human genetics and genomics are fundamental for the health biotechnology ecosystem and are critical components of the bioeconomy. ASHG's response includes actionable comments on genetics and genomics technology goals, community engagement models for diverse research participation, equitable workforce development, creating a responsible open data sharing ecosystem, and the responsible stewardship of human genomic data. By responding to this RFI, ASHG remains committed to integrating human genetics and genomics across all facets of research, medicine, and society to the benefit of all people.

# ASHG/NHGRI Genetics & Public Policy Fellowship Applications Open in Late February



ASHG and NHGRI co-sponsor the <u>Genetics & Public Policy Fellowship</u> to give genetics professionals an opportunity to contribute to the policy-making process. It is designed as a bridge for genetics professionals wishing to transition to a policy career. <u>Applications</u> for the 2023-2024 Genetics & Public Policy Fellowship will open in late-February and be due in late-April.

### **In Other News**

- On Dec. 29, 2022, President Biden signed the Consolidated Appropriations Act, 2023 (H.R. 2617) into law. The omnibus provides a total of \$47.5 billion for the NIH in FY 2023, an increase of \$2.5 billion (5.6%) above the FY 2022 enacted level, as requested by the Ad Hoc Group for Medical Research. ASHG signed on to this <u>community letter</u> in Nov. 2022.
- On Jan. 16, Kay Granger (R-TX), Chairwoman of the House Appropriations Committee, <u>announced</u> subcommittee leadership for the 118th Congress. Rep. Robert Aderholt (R-AL) will take on the role of chairman of the Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) subcommittee, which oversees funding for the NIH. Former Labor-HHS subcommittee chair Rep. Tom Cole (R-OK) will serve as the vice chair of the Appropriations Committee this Congress.
- Committee assignments are ongoing in Congress. The full <u>membership</u> of the House Energy & Commerce Committee was recently announced, which shares oversight responsibilities with the Senate Health, Education, Labor, and Pensions (<u>HELP</u>) Committee for the NIH, Centers for Disease Control, Food the Drug Administration, Agency for Healthcare Research and Quality, and other important health agencies. On Jan. 26, Senate majority Leader Chuck Schumer (D-NY) <u>announced</u> Senate Democratic committee membership.
- The U.S. reached the debt ceiling in mid-January. If a spending cap is implemented to hold FY 2024 funding to FY 2022 levels as a condition to raising the ceiling, this would mean <u>substantial budget cuts</u> for virtually all federal research agencies barely after the passage of FY 2023 funding. In coalition, ASHG continues to communicate to Congress the damage this would inflict on scientific advancement and biomedical research.
- On Jan. 18, *Roll Call* <u>published an article</u> regarding the vacant roles of NIH Director and Director of the National Institute of Allergy and Infectious Diseases (NIAID) at the start of the 118th Congress. The open positions previously held by Francis Collins, MD, PhD, and Anthony Fauci, MD, come at a time when the

administration has "big plans for advancing medical research," and while the agency is also the subject of a number of congressional oversight hearings.

- The next ELSI Friday Forum Seminar is on Feb. 10, 2023 Indigenizing Genomics and Advancing Indigenous Data Sovereignty - <u>Register here</u>. You can also watch the recordings of past seminars <u>here</u>.
- NIH, through the Office of Science Policy, <u>announced</u> the availability of administrative supplements to support research on bioethical issues that either inform future policy directions or augment bioethics research capacity. The application due date is **Feb. 17, 2023, by 5:00 PM local time** of applicant organization.
- <u>Registration</u> is still open for the 14th International Congress of Human Genetics in Cape Town, South Africa, Feb. 22-26, 2023. The closing date for in-person registration is **Feb. 18**, although virtual registration is also available.
- NHGRI and The State University of New York at Buffalo Center for Disability Studies held a two-day symposium on historical and present-day constructions of disability and ableism. <u>Watch the recordings</u> on GenomeTV and learn more about the history and lived experiences of people with disabilities in the context of genetics and genomics.

### **ASHG Calendar**

- On Feb. 16, continue the conversation on community engagement as a strategy to address
  underrepresentation in genomics research during "Successes in Community Engaged Research:
  Implementation of Recommendations in ASHG's Guidance, Addressing Underrepresentation in Genomics
  Research through Community Engagement." The webinar will highlight researchers successfully
  implementing the recommendations contained in ASHG's Guidance in their own projects.
- On Jan. 24, ASHG released the <u>report</u> of the "Facing Our History Building an Equitable Future" initiative. A <u>statement</u> from ASHG's Board of Directors acknowledges and apologizes for the involvement of early Society leaders in eugenics and its silence at times when genetics was used to feed racism; decries continued use of genetics to feed discrimination; and commits to sustaining and growing its efforts to advance equity.

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