



ADVOCATE UPDATE

May 2023

Trainee Advocates Communicate the Value of NIH Funding to Congress



This month, ASHG hosted its third year of virtual advocacy meetings on Capitol Hill. Current and former [trainee advocates](#) from the [Advocacy Certificate for Human Genetics and Genomics Trainees](#) (ACGT) program participated in this week-long advocacy activity. ACGT advocates shared how the NIH funds much of their research and called upon members of Congress to support robust funding for the NIH, efforts to diversify participation in human genetics research, and how continued biomedical research funding supports novel applications of genetic technology. Read more about this event in the summer edition of *The Messenger* newsletter - available in mid-June!



Add your voice by [contacting your members of Congress](#) in support of NIH funding for FY 2024. This is a great opportunity to participate remotely in ASHG's advocacy efforts and join in supporting policies that impact the research community.

ASHG Urges Strong Support for NIH Funding in Testimony to Senate



On May 18, ASHG 2023 President Brendan Lee, MD, PhD, [submitted](#) outside witness testimony on behalf of ASHG to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies in support of FY 2024 funding increases for the NIH. ASHG urged the Subcommittee to appropriate at least \$51 billion (+\$3.5 billion over FY 2023) for NIH's base budget in FY 2024. Advocates in the [Advocacy Certificate for Human Genetics & Genomics Trainees](#) (ACGT) program contributed examples of how advances in human genetics and genomics research benefit the health and well-being of all Americans.

ASHG Applauds the Inclusion of Genetics in White House Bioeconomy Report



The White House Office of Science and Technology Policy (OSTP) recently released a report entitled, [Bold Goals for U.S. Biotechnology and Biomanufacturing](#). This report incorporates themes gathered from the December 2022 public request for information (RFI) on the [National Biotechnology and Biomanufacturing Initiative](#) aimed at seeking innovative solutions to advance domestic biotechnology and biomanufacturing. The report sets ambitious national targets for the next two decades to help establish R&D priorities that will be critical to advance the bioeconomy. Echoing content in [ASHG's response to the RFI](#), the report outlines several priorities that incorporate the benefits and needs of human genetics and genomics research for its strategy. Albert Hinman, PhD, 2022-2023 ASHG/NHGRI Genetics & Public Policy Fellow, [summarizes](#) the Bold Goals report and highlights where insights provided by human genetics and genomics are fundamental for the health biotechnology ecosystem and are critical components of the bioeconomy.

Registration for the Rally for Medical Research is Now Open!



The 11th annual "Rally for Medical Research Hill Day" will take place on **Thursday, September 14, 2023**. In addition, there will be a reception during the early evening on Wednesday, September 13 to celebrate how federally funded research has contributed to health advances and saved lives. This event is an opportunity for supporters from the approximately 400 participating organizations (including ASHG) to join together and speak with one voice about making NIH funding a national priority. To learn more about the Rally for Medical Research, visit the [Rally website](#).

Registration is now available:

<https://www.surveymonkey.com/r/2023RallySignup>

In Other News

- In a [letter](#) to Congressional leaders, ASHG joined with 760 other organizations in the "non-defense discretionary" (NDD) community to reject cuts to NDD appropriations and communicate how cuts to NDD funding would be detrimental. Non-defense appropriations represent a small fraction of the federal budget but include important programs and services like scientific and medical research, medical care for veterans, environmental protections, support for K-12 education and skills training, and public health programs, among others.
- On May 15, President Biden [announced](#) his intent to nominate Monica Bertagnolli, MD, as director of the NIH. Dr. Bertagnolli has been serving as director of the National Cancer Institute since October 2022. The NIH director role will need to be confirmed by the Senate.
- On June 7, the National Academies will host a [hybrid public workshop](#) exploring the current use of DNA sequencing in newborns as well as the potential benefits and harms, associated ethical and data security issues, and equity in access to screening.
- The next ELSI Friday Forum will be held on June 9 at 12:00 PM ET. The webinar entitled, [Legal and Policy Challenges to Privacy in the Post-Genomic and Post-Dobbs Era](#), will discuss two emerging issues for genetic information: prenatal gene therapy and law enforcement access to DNA repositories from residual newborn screening.
- On May 3, Senate Majority Leader Chuck Schumer (D-NY) [launched](#) a new legislative initiative to expand on provisions omitted from last year's CHIPS and Science Act to create a "China Competition Bill 2.0" aimed at bolstering U.S. competitiveness. Bill language will focus on policy areas including limiting the flow of advanced technology to the Chinese government and securing domestic economic investment (e.g., in biotech). ASHG is monitoring for language that could impose a national security framework on genomic data or discriminate against Chinese researchers.
- On May 4, the Senate Labor-HHS Appropriations Subcommittee held a hearing on the President's FY 2024 budget request for the NIH. A recording is available [here](#).
- [The Center for ELSI Resources and Analysis](#) (CERA) has a new resource entitled, [Engaging Underrepresented Communities in Research](#). CERA interviewed researchers working on four projects focused on populations underrepresented in genomic and precision medicine research: adults with intellectual disability, older African Americans, Puerto Ricans, and North Kenyan pastoralists.
- A recording of the National DNA Day 20th Anniversary Symposium is now available on the National Human Genome Research Institute [website](#) and YouTube channel, [GenomeTV](#). ASHG celebrated with an announcement of our DNA Day Essay Contest [winners!](#)

ASHG Calendar

- [Registration](#) for ASHG 2023 is open. Register before August 24 to get the early bird rate!
- [Abstract submissions](#) for ASHG 2023 are due **by June 8**.
- Applications are now open for the [Human Genetics Scholars Initiative](#), a program advancing diversity, equity, and inclusion in the genetics and genomics workforce. To apply for this two-year, intensive program, applicants [must submit an abstract](#) to the [2023 ASHG Annual Meeting](#). HGSI applications close **June 16** and abstracts are due **June 8**.

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