

#### **June 2023**

# **ACGT Advocates Reflect on ASHG's 2023 Capitol Hill Meetings**



Read the reflections on ASHG's 2023 Hill engagement virtual meetings from trainee advocates in the Advocacy Certificate for Human Genetics and Genomics Trainees (ACGT) program. 2022 ACGT advocate Rene Begay, MS, CPH, explained why continued engagement with Congress is needed. "It is important to continue to engage with and inform members of Congress and their staff about why and how scientists conduct research in order to improve human health. Engaging with them helps to solidify support for research, particularly genetics research. Many times, the conversations with these members are about finding common interests to learn from one another so we can work together to move scientific initiatives forward. It is our job as scientists to relay why genetics research is important and how our results make a difference in the world." Read more about this advocacy event in *The Messenger* newsletter available now!

## **Reductions to Research Funding in Debt Limit Agreement**



On June 3, President Biden signed the Fiscal Responsibility Act of 2023 into law. The bill avoids a default on the country's finances by suspending the borrowing limit through Jan. 1, 2025, while also imposing cuts to future federal spending over the next two years. Spending levels for FY 2024 include \$637 billion for most nondefense discretionary (NDD) programs (including NIH), effectively freezing spending at \$1 billion below the current FY 2023 level. Under the budget environment set by the bill, new R&D initiatives could have limited funding. However, the deal also includes "flexible" funding not written into the bill for future NDD spending, which represents an opportunity for sustained research funding. As an additional incentive for Congress to complete the FY 2024 appropriations process during the calendar year, sequestration (i.e., automatic spending cuts) would reduce spending limits to 1% below the FY 2023 base funding levels if a continuing resolution is in effect on or after January 1, 2024. If all regular appropriations bills are enacted before April 30, 2024, the revised limits revert to the original limits. Learn more about the impact to R&D from the American Association for the Advancement of Science (AAAS).

With appropriations markups resuming this month, it is critical to engage with Congress to share the priorities of researchers like yourself. Take action <a href="https://example.com/here/">here!</a>

# ASHG Joins Community Letter in Support of Monica Bertagnolli, MD's Confirmation as NIH Director



In May, President Biden <u>nominated</u> National Cancer Institute Director Monica Bertagnolli, MD, to be the next director of the NIH. In June, a <u>letter of support</u> was delivered to Senate leadership and leaders on the Senate Committee on Health, Education, Labor and Pensions (HELP). Signed by 115 scientific and medical non-profit organizations, the letter acknowledges Dr. Bertagnolli as a leading scientist, surgeon - and a patient herself - and urges members of the Senate to swiftly confirm her appointment. The NIH has been without a permanent director since December 2021, with Larry Tabak, DDS, PhD, serving as Acting NIH Director since the resignation of physical-geneticist Francis Collins, MD, PhD.

FY 2024 Appropriations Resume in June



The House Appropriations Committee <u>approved subcommittee</u> <u>allocations</u> (called '302(b) levels') for each of the 12 FY 2024 spending bills, although with lower funding allocations than those outlined in the *Fiscal Responsibility Act of 2023* (FRA). House Appropriations Chair Rep. Kay Granger (R-TX-12) <u>released a statement</u> on June 12 asserting that the FRA discretionary number is "a ceiling, not a floor." The Senate recently <u>released</u> their 302(b)s with topline numbers that more closely align with those in the FRA.

Follow along with the appropriations process by using this handy AAAS tool.

# Registration for the Rally for Medical Research is 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 open: <a href="https://www.surveymonkey.com/r/2023RallySignup">https://www.surveymonkey.com/r/2023RallySignup</a>

### **In Other News**

- Senators Thom Tillis (R-NC) and Chris Coons (D-DE) recently introduced a new
  version of the <u>Patent Eligibility Restoration Act</u>, which seeks to modify Section 101 of
  the U.S. Patent Act. If passed, the legislation would allow for the patenting of genes
  that are isolated or purified in a lab. ASHG's position <u>opposing gene patenting</u> is
  unchanged, and the Society is engaged with the American College of Medical Genetics
  and Genomics (ACMG) and other advocacy partners on next steps.
- The Ad Hoc Group for Medical Research released a <u>press statement</u> on the FY 2024 appropriations process, urging Congress to act now to provide the NIH with at least \$51 billion in FY 2024.
- The next ELSI Friday Forum webinar will be held on July 14 at 12 pm ET Population Descriptors in Genomic Research: Applying the NASEM Recommendations - <u>Register</u> here.
- The Coalition for the Life Sciences (CLS) and Federation of American Societies for Experimental Biology (FASEB) will once again host the <u>Congressional Life Science</u> <u>Fair</u> on July 19 in the Rayburn House Office Building from 5 pm - 7 pm. This is a way for organizations and scientists to showcase their work with members of Congress and their staff and provide attendees with the opportunity to engage in hands-on experiments. ASHG will staff a table at this event.
- President Biden <u>has selected</u> former North Carolina health secretary Mandy Cohen, MD, MPH, to lead the Centers for Disease Control and Prevention (CDC). Dr. Cohen will replace Rochelle Walensky, MD, MPH, who is stepping down as head of the agency on June 30.
- The Global Alliance for Genomics and Health (GA4GH) <u>recently updated</u> its strategic plan to emphasize clinical interoperability of genomic data and enable greater responsible use of genomic and related health data.

### **ASHG Calendar**

- Registration for ASHG 2023 is open! Register before August 24 to get the early bird rate!
- ASHG was <u>awarded</u> a five-year, \$7.1 million contract for an expanded Genomics and Public Service Fellowship Program. All fellowships opportunities - including the graduate-level <u>Genetics & Public Policy Fellowship</u> - will open in fall 2023.
- If you missed the June Journal Club: Exploring Patterns of Mosaicism in One Million People, you can watch the recording at the <u>ASHG Learning Center</u>.
- July Journal Club: <u>The commonality of TSPEAR-related ARED14 sheds light on human origins</u>, July 12 at 12 PM ET.
- ASHG attended the European Society of Human Genetics (ESHG)'s <u>annual meeting</u> earlier this month, showcasing the Society's ongoing work and catching up on the international dialogue in the field.

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