

Ad Hoc Group Weekly Round Up – March 4, 2019

Each week, the Ad Hoc Group Weekly Round Up will feature hashtags and/or tweets (follow us at [@fundNIH](#)) suggested by members of the National Institutes of Health (NIH) advocacy community. We encourage all readers who are active on social media to use these messages, and we welcome suggestions from the community for future issues of the Weekly Round Up. Here is this week's featured tweet:

[Tannaz Rasouli @ tannaz](#)

DYK? Untreated hearing loss is considered one of nine modifiable risk factors for dementia. Research supported by [@NIH's @NIDCD](#) at medical schools & teaching hospitals focuses on ways to prevent and treat hearing loss and other communication disorders.

[#ResearchMeansHope](#) [#fundNIH](#)

1. House FY 2020 Public Witness Testimony, Member Submissions

The House Appropriations Labor-HHS Subcommittee will host a Public Witness Hearing on Tuesday, April 9. The deadline to submit requests to testify is Tuesday, Mar. 19, while the deadline to submit written testimony for the record is Monday, April 8. The complete notice and instructions are posted on the subcommittee [website](#).

In addition, the Labor-HHS Subcommittee [has announced](#) a March 28 deadline for Members of Congress to submit their FY 2020 appropriations requests to the Labor-HHS spending bill, in addition to a [Dear Colleague letter](#) from Chair Nita Lowey (D-N.Y.) noting that earmarks will not be considered for FY 2020 spending bills.

2. Retired Admirals and Generals Urge Congress to Raise Defense and Non-defense Discretionary Spending Caps for FY 2020

Nearly 350 retired admirals and generals and current members of the national security organization Mission: Readiness, sent a Feb. 27 [letter](#) to all Members of Congress urging support for programs that “help America’s children grow into healthy, educated, citizen-ready adults.” Specifically, they urge Congress to raise “spending caps mandated by the Budget Control Act of 2011 (BCA) and provide balanced investments in both defense and non-defense discretionary (NDD) programs” for fiscal years (FY) 2020 and 2021.

Senate Appropriations Committee Vice Chair Patrick Leahy (D-Vt.) echoed the letter’s sentiments in a Feb. 28 [floor speech](#), where he told his colleagues, “We must begin negotiating a two-year budget deal now ... [that is] based on parity – equal treatment for defense and non-defense programs. We need to invest on both sides of the ledger if we are to create a strong national defense, a strong economy, and a healthy citizenry.”

3. NIH Shares Update on Efforts to Address Sexual Harassment in Science

The NIH Feb. 28 released [a statement](#) on its efforts to address sexual harassment, signed by Director Francis Collins, MD, PhD, and other NIH leadership, stating, “NIH has been part of the problem...We are determined to become part of the solution.” The statement also announced that “in 2018, NIH followed up on sexual harassment-related concerns at more than two dozen institutions resulting in the replacement of 14 principal investigators named on NIH grant awards, disciplinary actions taken by awardee institutions against 21 principal investigators including termination of employment, and removal of 14 individuals from peer review.”

The [working group of the Advisory Council to the Director \(ACD\) on Changing the Culture to End Sexual Harassment](#) held its first meeting in February and plans to report interim recommendations in June and provide a final report in December. In the meantime, the NIH leadership outlined the actions they intend to continue taking. NIH Deputy Director for Extramural Research Michael Lauer, MD, relayed the letter in an *Open Mike* [blog post](#) and also linked to the NIH [Anti-Sexual Harassment webpage](#).

4. NIH Director's Blog: Rare Disease Day

NIH Director Francis Collins, MD, PhD, Feb. 28 published a [blog post](#), "Thoughts from the Front Lines of Rare Disease Research" to coincide with Rare Disease Day. Dr. Collins shares excerpts from an interview with Harper Spero, a patient with a rare disease and a participant in medical research. Spero notes that, "Without research, we can't make any improvements, changes or find cures. Participating in medical research allows researchers and doctors to learn about the trends (or lack of) between patients, and determine what's working and what's not."

5. *Nature*: Update on NIH's Accelerating Medicines Partnership

A Feb. 27 [news article](#) in *Nature* shares updates on a five-year old collaboration between NIH, academia, and industry, aimed at speeding up drug discovery, the Accelerating Medicines Partnership (AMP). The program began in 2014 with an initial budget of \$230 million, and has increased to \$360 million, focusing on four disease areas: Alzheimer's disease, diabetes, rheumatoid arthritis and lupus, and Parkinson's disease. NIH Director Francis Collins, MD, PhD, notes, "by working with industry and academia at the same table, focused in this precompetitive space, there's been pretty dramatic progress... By any measure, this [program] has lived up to expectations."

6. *Open Mike* Blog: Seeking Input on Accessibility of NIH Grants Data

NIH Deputy Director for Extramural Research Mike Lauer, MD, published a Mar. 4 [blog post](#) highlighting a [request for information](#) (RFI) "to gauge interest in NIH expending funds to develop, host, and maintain a secure environment (data enclave) that would allow approved research organizations-controlled access to structured, de-identifiable NIH administrative and scientific information not made available to the public." Dr. Lauer notes that the RFI responses will inform NIH's decisions on data accessibility as it begins "exploring the costs and benefits of providing approved research organizations-controlled access to such structured, de-identifiable NIH administrative and scientific information in a formal and controlled way—through a secure data enclave."

Upcoming Hill Briefings and Other Events

7. Allen Institute Briefing on Philanthropic Investments in Research – Mar. 6

The Allen Institute invites you to a congressional briefing highlighting how philanthropic investments in scientific research are amplifying the federal government's funding of public research at agencies like the National Institutes of Health (NIH). The briefing will take place on Wednesday, Mar. 6 with the Senate briefing from 2:00 - 3:30 PM in Senate Visitors Center (SVC) 215, and the House briefing from 4:00 - 5:30 PM in 2103 Rayburn House Office Building. Please see attached event invitations for further details and RSVP to rsvp@petrizzogroup.com.

8. AEVR Congressional Briefing – Mar. 6

The Alliance for Eye and Vision Research is co-hosting a Congressional briefing titled "Understanding the Genetic Basis of Glaucoma to Develop Vision Loss Prevention Strategies." The lunch briefing will take place on Mar. 6 from 12:00-1:15 pm in 2168 Rayburn House Office Building. Please see attached flyer for additional information.

9. Congressional Briefing on Nonhuman Primate Research – Mar. 6

The Supporting Truth About Animal Research coalition is hosting a Congressional briefing titled "Research with Nonhuman Primates: Advancing Health and Scientific Knowledge." The briefing will take place on Mar. 6 from 12:00-1:30pm in 385 Russell Senate Office Building. Please see attached flyer for additional information. [RSVPs](#) are required.

10. Biophysical Society Congressional Briefing – Mar. 13

Please join the Biophysical Society and Congressman Bill Foster (D-IL) for a CRISPR-101 briefing presented by Jennifer Doudna, PhD, on Mar. 13 from 10:30 - 11:30am in 2168 Rayburn House Office Building. This briefing is designed for new Members of Congress and staff and will provide a broad overview of the technology, discuss its ethical use and patenting issues, and is intended for a lay audience. Please see attached flyer for additional information. To RSVP [please fill out this form](#) or contact Sean Winkler at swinkler@biophysics.org.

11. CLS Congressional Briefing: NIH 101 – Mar. 14

The Coalition for the Life Sciences is hosting a Congressional briefing titled "NIH 101: An Introduction to the National Institutes of Health" on Mar. 14 from 12-1pm in 122 Cannon House Office Building. Please RSVP to cls@coalitionforlifesciences.org and see attached flyer for additional information. The briefing is the first in a series, see attached for full briefing calendar.

12. AAMC/FASEB Webinar on NAS Integration of Humanities and STEM Report – Mar. 18

The Association of American Medical Colleges (AAMC) and the Federation of American Societies for Experimental Biology (FASEB) are hosting the fourth webinar in their 2018 National Academies reports [webinar series](#). Study director Ashley Bear, PhD, of the National Academies, will unpack the key findings of the report "[The Integration of the Humanities and Arts with Sciences, Engineering and Medicine in Higher Education: Branches of the Same Tree](#)," in a Mar. 18 webinar, from 1:00-2:00 PM ET. Free [registration](#) is required.

13. NIH ACD Meeting: June 13-14

In a [Federal Register notice](#), the NIH announced the next Advisory Committee to the Director meeting will be held June 13-14 at the National Institutes of Health, Natcher Building, Conference Room D, 45 Center Drive, Bethesda, MD 20892. Preliminary agenda items include: the NIH Director's Report, ACD Working Group Reports, and Other Business of the Committee.

Job Postings

AACR Seeks Director, Congressional Relations

The American Association for Cancer Research seeks a [Director of Congressional Relations](#) to: provide specialized expertise and support to AACR leaders, including the Science Policy and Government Affairs Committee, its relevant subcommittees, and broader partners in the

community to further the goals of the AACR's Strategic Plan and policy priorities. To apply, please submit your cover letter and resume humanresources@aacr.org.

Academy for Radiology & Biomedical Imaging Seeks Director of Communications and Membership

The Academy is seeking an experienced professional for a Director of Communications and Membership, to maintain and improve organizational branding and messaging for internal and external communications. This position will work with a two-person communications staff to create and execute a range of activities intended to raise awareness of our mission and work, as well as the state of policy and grassroots efforts to our membership. Please see attached for additional information. Applications can be sent to ETownley@acadrad.org.

PCORI Seeks Associate Director, Public Policy

The Patient-Centered Outcomes Research Institute seeks an Association Director, Public Policy. Position responsibilities include: supporting the Director for Public Policy and Government Relations, Chief Engagement and Dissemination Officer, and the PCORI Board of Governors and executives in representing PCORI with Congress; and more. Please visit the [job posting](#) to apply.

ASHG Seeks Policy and Advocacy Manager

ASHG also seeks a Policy & Advocacy Manager help fulfill the Society's policy and advocacy functions by tracking, analyzing and drafting material on policy issues; staffing volunteer bodies to develop policy material and advocacy programming; helping to build and then manage advocacy activity of Society's leadership and membership; and strengthening relations with Congress. Please visit FASEB's [employment opportunities](#) site to learn more and to apply.

University of Florida Seeks Assistant Director of Federal Relations

The University of Florida Seeks an Assistant Director of Federal Relations for the Washington, D.C. office. Essential job functions include: manage and execute the government relations program for a portfolio of the University's federal interests; anticipate, monitor and analyze federal policy; and more. Details and application instructions are available on the [job posting site](#).

American Heart Association Seeks Regulatory Affairs Manager

Under the direction of the Vice President of Federal Advocacy, the [Regulatory Affairs Manager](#) would be responsible for monitoring, analyzing, and drafting responses to a prescribed set of federal regulatory and reimbursement-related issues that impact the association's public policy agenda. The primary focus of the AHA's regulatory work is with the Department of Health and Human Services and its key agencies.

Please Note: If you have information of interest to the NIH advocacy community that you would like to share with the Ad Hoc Group, please forward it to Christa Wagner at chwagner@aamc.org or Tannaz Rasouli at trasouli@aamc.org.