

## Ad Hoc Group Weekly Round Up – March 12, 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:

### [60 Minutes @60Minutes](#)

“Someday we're gonna have a cure for sickle cell anemia.’ Dr. Jon LaPook describes the ‘helpless feeling’ he had treating sickle cell patients early in his career and how it was ‘especially emotional’ for him to report on what may be a cure for the disease <https://cbsn.ws/2HfrX4P>.”

### 1. President’s Budget Request Seeks Drastic Cuts to NIH

The President’s FY 2020 [budget request](#) and HHS [Budget in Brief \(BIB\)](#) document released Mar. 11 proposed a \$34.4 billion budget for the NIH, a \$4.7 or more than 12 percent cut to NIH below the FY 2019 program level. Further detail is expected with the release of Congressional Justification documents the week of Mar. 18.

The Ad Hoc Group for Medical Research responded to the budget release with a [press statement](#) noting that the request “would decimate the nation’s longstanding commitment to improving and saving lives through federal support for medical research.” In the statement, the coalition thanked Congress for its recent commitment to NIH, and urged lawmakers to “enact swiftly a bipartisan budget agreement that raises the discretionary spending caps and enables a robust investment in NIH in FY 2020.”

### 2. Ad Hoc Sends FY 2020 Funding Recommendation to Congress

The Ad Hoc Group for Medical Research, a coalition of more than 300 organizations and institutions across the NIH stakeholder community recommend an appropriation of at least \$41.6 billion for the NIH in FY 2020, a \$2.5 billion increase over the NIH’s program level funding in FY 2019. This funding level would allow for meaningful growth above inflation in the base budget that would expand NIH’s capacity to support promising science in all disciplines. It also would ensure that funding from the Innovation Account established in the 21st Century Cures Act would supplement the agency’s base budget, as intended, through dedicated funding for specific programs. See the full statement and list of endorsers [here](#).

### 3. House Appropriations Committee Hearing on Labor-HHS Budget

The House Appropriations Subcommittee on Labor-HHS [will hold](#) a hearing on the President’s FY 2020 budget request on Wednesday, Mar. 13 at 2pm in 2358-C Rayburn House Office Building. HHS Secretary Alex Azar will testify.

### 4. 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.

### **5. 60 Minutes: NIH's Sickle Cell Disease Program**

The CBS news show *60 Minutes* on Mar. 10 [highlighted](#) NIH's sickle cell anemia gene therapy treatment program through the eyes of one patient during her treatment at NIH's Clinical Center. In the episode, NIH Director Francis Collins, MD, PhD, shares the story of his budding interest in genetics when he met a sickle cell patient as a medical student. The report notes that eight adults have undergone gene therapy treatments for sickle cell, and are "responding well." Dr. Collins wrapped up by sharing his dream of using this same gene therapy strategy for the 7,000 other conditions with known genetic causes.

### **6. FDA Approves First Major Antidepressant in Decades**

The [New York Times](#) reported that FDA Mar. 5 approved esketamine a version of the anesthetic ketamine, as a prescription treatment for depression. Of note, treatment of depression with ketamine "took off in 2006, when a team at the National Institute of Mental Health [NIMH] led by Dr. Carlos Zarate Jr. reported that 18 treatment-resistant people who received the drug intravenously [reported that their despair lifted within hours](#)" in comparison to the currently available Prozac and similar drugs which take much longer to have an effect. This follows [years of preliminary research](#) at academic medical centers into the underlying mechanisms of depression and suicide.

### **7. NIH Commitment to Transparency in Pathogen Research**

NIH Director Francis Collins, MD, PhD, Mar. 5 [provided an update](#) on potential pandemic pathogen research supported by NIH. Research on such pathogens, like seasonal influenza, was paused from 2014 to 2017 in response to public concern about research safety, resulting in HHS's "[Framework for Guiding Funding Decisions about Proposed Research Involving Enhanced Potential Pandemic Pathogens](#) to provide an additional level of review and oversight to help ensure such research is conducted with the utmost regard to safety and security." Recently, two proposals were awarded funding for research in the scope of this HHS framework.

### **8. New Committee to Help Address Pain and Addiction in HEAL Initiative**

NIH Director Francis Collins, MD, PhD, Mar. 5 also [announced](#) the formation of the HEAL Partnership Committee (HPC), a subgroup of the HEAL Multi-Disciplinary Working Group to aid in informing research efforts "to develop new, non-addictive medications and medical technologies that reduce the need for opioids." The HPC is made up of "experts in drug and medical device development, research, and bioethics, and includes critical patient representation." In tandem, NIH has signed a memorandum of understanding with three industry professional organizations to assist the HEAL Initiative in reaching its goals and to identify opportunities to provide scientific expertise.

## **Upcoming Hill Briefings and Other Events**

### **9. 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](mailto:swinkler@biophysics.org).

### **10. UMR Congressional Briefing on Research in Rural States – Mar. 13**

Please join United for Medical Research at a Congressional Briefing to release their new report “How NIH-Funded Research Benefits Rural States.” The briefing will take place Wednesday, Mar. 13, from 12-1:30pm in U.S. Capitol Room S-115. Please see attached for additional information, and RSVP to [umr@hudsonlake.com](mailto:umr@hudsonlake.com).

### **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](mailto: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. BPS Congressional Briefing on Cryo-EM – Mar. 26**

The Biophysical Society is hosting a Congressional Briefing: “The Cryo-EM Revolution Reaping the Benefits of a Nobel Prize-Winning Molecular Imaging Breakthrough and What the Future Holds.” The briefing will take place Mar. 26 from 4-6pm in 2060 Rayburn House Office Building. Please see attached flyer for additional details, and RSVP [here](#).

### **14. American Thoracic Society Briefing on TB – Mar. 27**

Please join the American Thoracic Society at a World TB Day Congressional Briefing: “Tuberculosis: New Momentum to Combat the Top Global Infectious Killer.” The briefing will take place on Wednesday, Mar. 27, from 12-1:30 pm in 2200 Rayburn House Office Building. See attached for additional information, and RSVP [here](#).

### **15. NIH Regional Seminar in Baltimore, MD: May 15-17**

The NIH is hosting the Spring 2019 NIH Regional Seminar on Program funding and Grants Administration in Baltimore, MD, from Wed. May 15- Fri. May 17. Visit the [website](#) to learn more about the [program](#) and to [register](#).

## **16. 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](mailto: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](mailto:ETownley@acadrad.org).

#### **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](mailto:chwagner@aamc.org) or Tannaz Rasouli at [trasouli@aamc.org](mailto:trasouli@aamc.org).