

## Ad Hoc Group Weekly Round Up – December 3, 2018

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:

**National Human Genome Research Institute [@genome\\_gov](#)**  
**#ICYMI** Dr. Jennifer Doudna talks CRISPR in our most popular [#RedditAMA](#)  
<http://bit.ly/2QokhS0>

### 1. Leadership Selections for 116<sup>th</sup> Congress

House Democrats Nov. 28 held leadership elections, where Rep. Nancy Pelosi (D-Ca.) won her party's nomination to be Speaker of the House; the full House will vote on her nomination in January. Additional Democratic leadership for the 116th Congress includes: Majority Leader Steny Hoyer (D-Md.); Majority Whip James Clyburn (D-S.C.); and Assistant Majority Leader Ben Ray Lujan (D-N.M.). House Republicans Nov. 29 voted Kay Granger (R-Texas) to be the next Ranking Member of the House Appropriations Committee. House Republicans also Nov. 14 held leadership elections for the 116<sup>th</sup> Congress, electing the following roles: Minority Leader Kevin McCarthy (R-Calif.); Minority Whip Steve Scalise (R-La.); and Conference Chair Liz Cheney (R-Wyo.).

The Senate Nov. 14 held leadership elections for the 116th Congress. While members of the Senate Democratic leadership in the 115th Congress will continue in their roles, Senate Republicans will see changes due to term limits. The Senate Republican leadership for the 116th Congress includes: Senate Majority Leader Mitch McConnell (R-Ky.); Majority Whip John Thune (R-S.D.); and Senate Republican Conference Chairman John Barrasso (R-Wyo.).

### 2. Joint Select Committee Concludes Without Advancing Budget Reform Legislation

The Joint Select Committee on Budget and Appropriations Process Reform [Nov. 29](#) failed to achieve the 10 votes needed to advance the measure. The final vote was 7-5, with four members voting "present." The vote followed the Select Committee's [Nov. 27](#) continued markup of proposed legislative changes to the current budget and appropriations process.

The Select Committee's legislation proposed moving to a biennial budgeting process, adjusting Congress's deadline for budget submission from April 15 to May 1, and requiring the Executive branch to provide a new annual supplemental budget submission by Dec. 1 of each calendar year. A total of 10 yeas were required for passage out of committee, including five from Republican and five from Democratic Select Committee members. The Select Committee was to remain in existence until the deadline to report its final bill on Nov. 30.

### 3. NIH Statement on Claim of First Gene-Edited Babies by Chinese Researcher

NIH Director Francis Collins, MD, PhD, expressed concern in a Nov. 28 [press statement](#) regarding claims of Chinese scientist He Jiankui, PhD, that he used the gene-editing tool CRISPR to edit human embryos, resulting in the births of twin girls. Dr. Jiankui claims to have targeted a cell membrane protein that allows HIV to enter cells in an effort to prevent future HIV infection. Dr. Collins' concerns included that the work "was largely carried out in secret, the

medical necessity for inactivation of [the protein] in these infants is utterly unconvincing, the informed consent process appears highly questionable, and the possibility of damaging off-target effects has not been satisfactorily explored." Dr. Jiankui's [claims have not gone through peer review](#) for publication in a scientific journal. Additionally, Chinese scientists [signed a letter](#) condemning the research, and the Chinese government [has halted the work](#) leading to these children as it investigates. Dr. He has since [claimed](#) that there is a second pregnancy with gene-edited embryos, although it is still in its early stages.

#### **4. Oversight and Government Reform Hearing on Alternatives to Fetal Tissue Research – Dec. 6**

The House Oversight and Government Reform Subcommittees on Government Operations and Healthcare, Benefits, and Administrative Rules [will hold](#) a joint hearing titled "Exploring Alternatives to Fetal Tissue Research." The hearing will be held in 2154 Rayburn House Office Building beginning at 10 a.m.

#### **5. *Open Mike*: New Funding Opportunities for Basic Experimental Studies Involving Humans**

In a Nov. 28 *Open Mike* [blog post](#), NIH Deputy Director of Extramural Research Mike Lauer, MD, and NIH Associate Director of Behavioral and Social Sciences Research William T. Riley, PhD, discuss upcoming new funding opportunities for basic experimental studies involving humans. These opportunities have been provided in response to community input regarding registering and reporting for studies that "meet the [NIH] definition of basic research and also are subject to clinical trials policies based on the [NIH definition of a clinical trial](#)." NIH is also "postponing enforcement of the [NIH Policy](#) on the Dissemination of NIH-Funded Clinical Trial Information for studies submitted to Basic Experimental Studies with Humans [Funding Opportunity Announcement]. NIH will continue to expect registration and results reporting for these studies but is allowing additional flexibility to report on alternative portals instead of ClinicalTrials.gov."

#### **6. NIH Releases Data Book Update**

The NIH released in November its online [Data Book](#), providing summary statistics on extramural grants and contract awards, grant applications, organizations that NIH supports, trainees and fellows supported through NIH programs, and the national biomedical workforce.

#### **7. NIH Op-Ed in *USA TODAY* on Suicide Prevention**

NIH Director Francis Collins, MD, PhD, and NIMH Director Joshua Gordon, MD, PhD, co-authored a Nov. 28 [USA TODAY op-ed](#) about NIH's commitment to reducing suicide. Drs. Collins and Gordon share that "research demonstrates that most individuals who die by suicide suffer from some form of mental illness, whether diagnosed or not. Annually, NIH spends an estimated \$68 million on suicide and suicide prevention research and an additional \$2.7 billion on mental health research. By improving the diagnosis and management of mental illnesses, we can effectively reduce the risk of suicide." Their opinion comes in response to a Nov. 28 [USA TODAY editorial](#) suggesting that NIH does not spend enough of its budget on suicide prevention.

#### **8. Podcast: NIH Director Discusses Implications of the Human Genome Project**

NIH Director Francis Collins, MD, PhD, participated in a Nov. 26 Bloomberg [Prognosis podcast](#) titled “Decoding the Genome was Just the Beginning.” The summary shares: “Eighteen years ago, scientists decoded the human genome. But what was supposed to create an era of new cures didn’t work out that way, at least not at first. In episode four of *Prognosis*, some of the most famous names in genetics explain why it took so long to go from mapping life’s code to actually helping people, laying the foundations for technologies on the scientific and ethical cutting edge, like modifying people’s genes.”

#### **9. *Politico*: NIH’s Challenge for All of Us is Building Trust**

Reporter Mohana Ravindranath of *Politico* (subscription required) [Dec. 3](#) writes that NIH’s big challenge for the All of Us project is to build trust with minority and underserved populations to encourage their participation in the program. All of Us’ Chief Engagement Officer Dara Richardson-Heron, MD, shares her contributions to building that trust, by clearly outlining the protections established to guard participants’ data and privacy, and also to communicate the values of participating in the research program.

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

#### **10. Crohn’s and Colitis Foundation Congressional Briefing – Dec. 6**

More than 3 million Americans live with Crohn’s disease or ulcerative colitis. These diseases affect people of all walks of life, regardless of age, sex, race, ethnicity, or sexual orientation; yet little is understood about the impact these diseases have on racial and ethnic minorities. Please join the Crohn’s & Colitis Foundation and their partners for a Crohn’s & Colitis Awareness Week discussion about what is known to date and what the Centers for Disease Control and Prevention is doing to elucidate the impact of these expensive-to-treat conditions on population health. The lunch briefing will take place on Thursday, Dec. 6 from 12-1pm in 562 Dirksen Senate Office Building. Please RSVP to Charla Ramsey at [Charla.Ramsey@FaegreBD.com](mailto:Charla.Ramsey@FaegreBD.com) and see the attached flyer for additional information.

#### **11. NIH ACD Meeting – Dec. 13-14**

The NIH Advisory Council to the Director (ACD) will hold a public meeting Dec. 13 from 8:30am-5:30pm and Dec. 14 from 9am – 12pm at the NIH. Details are available through a [Federal Register notice](#), and will become available on the [NIH ACD website](#). Agenda items include the NIH Director’s report and ACD Working Group reports.

#### **Job Postings**

##### **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, including members, committee staff and legislative staff; support the development and implementation of PCORI’s strategic plan related to reauthorization; and more. Please see attached flyer for additional details, and contact PCORI Director for Public Policy and Government Relations Andrew Hu [ahu@pcori.org](mailto:ahu@pcori.org) 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, funding developments, legislation and regulations, and provide regular reporting to internal stakeholders; build and maintain relationships with key legislative branch and executive branch officials, their staff members, and higher education and other policy advocates and associations; and more. More details and application instructions are available on the [job posting site](#).

### **AAU Seeks Assistant/Associate VP for Federal Relations**

The Association of American Universities, an association of 62 leading public and private research universities, seeks applications for the position of Assistant/Associate Vice President for Federal Relations. This position reports to the Executive Vice President & Vice President for Federal Relations.

Applicants should have: (1) strong leadership, advocacy, negotiating, analytic, strategic planning, and communication skills; (2) expertise and/or experience with federal research policy and funding issues, especially related to research sponsored by the U.S. Departments of Defense and Energy; (3) experience engaging with Congress, the Executive Branch, and/or policymakers at other levels of the federal government; (4) the ability to work effectively and collegially with representatives of member universities, other organizations, and coalitions; and (5) the ability to succeed in a dynamic, fast-paced work environment involving many individuals with different backgrounds and interests. Please see the [job posting](#) for additional details. To be assured of full consideration, please send a cover letter, resume and salary requirements by December 5, 2018 to [jobs@aau.edu](mailto:jobs@aau.edu) (Please refer to Assistant/Associate Vice President for Federal Relations in the subject line).

### **American Heart Association Seeks Government Relations Manager on Appropriations and Regulatory Affairs Manager**

This [Government Relations Manager](#) represents the American Heart Association before Congress and the Executive Branch agencies on legislative and regulatory issues related to biomedical research heart disease and stroke prevention programs. Responsibilities include: developing and executing appropriations requests before the House and Senate Labor Health and Human Services, Education and Related Agencies Appropriation Subcommittees for the National Institutes of Health (NIH) and for heart disease and stroke prevention programs administered by the Centers for Disease Control and Prevention (CDC). This position is also responsible for developing knowledge and expertise (and when applicable, advocacy positions) related to all issues relevant to the research environment, among other roles.

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: Centers for Medicare and Medicaid Services, Food and Drug Administration, and Health Resources and Services Administration. Major topics would include rules that impact ACA markets and patient protections, Medicare coverage determinations and Medicare payment rules, and FDA initiatives focused on drug/device development and safety.

### **Christopher and Dana Reeve Foundation Seeks Policy and Advocacy Coordinator**

The Christopher and Dana Reeve Foundation seeks a motivated individual to join a policy team committed to making a difference in the lives of people with paralysis and/or mobility impairments. The [Policy and Advocacy Coordinator role](#) will offer an opportunity to learn more about the issues and initiatives that the Reeve Foundation is working on to address the difficulties faced by people with paralysis and their families and help support and advance that work. The role will also offer an opportunity to oversee the Reeve Foundation's Regional Champions grassroots advocacy education program. To apply, please send resume along with cover letter by email to Felice Fullem at: [ffullem@christopherreeve.org](mailto:ffullem@christopherreeve.org).

### **COSSA Seeks Candidates for Staff Assistant**

The Consortium of Social Science Associations (COSSA) is seeking to fill the position of Staff Assistant. The Staff Assistant will provide critical support to COSSA team members on a variety of activities and tasks. The primary functions of this position fall into two categories: (1) Administrative and Membership Support; and (2) Research and Policy Support. The position reports directly to the Executive Director and requires close collaboration with the entire team. This is a full-time, exempt position. In addition to salary, benefits include medical, dental, life and disability insurance, paid annual and personal leave, and employee pension once eligibility requirements are met. Additional details are in the attached flyer. Interested applicants should send a resume, cover letter and salary history to [jobs@coffa.org](mailto:jobs@coffa.org) by December 7, 2018.

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).