

## Ad Hoc Group Weekly Round Up – November 26, 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:

### Research!America ([@ResearchAmerica](#))

*"The total U.S. investment in medical and [#health](#) [#research](#) and development in the U.S. grew by 27% from 2013 to 2017, but is this enough? More than half of the U.S. public doesn't think so. <https://bit.ly/2Fx2CmV>."*

### 1. Joint Select Committee on Budget and Appropriations Continues Markup

The Joint Select Committee on Budget and Appropriations Process Reform Nov. 27 will continue to mark up its proposed legislative language, which began during a [Nov. 15 markup](#). The meeting will take place in 1334 Longworth House Office Building beginning at 2pm.

### 2. Update on Cancer Moonshot – Moving from Planning to Research

Co-Chair of the Cancer Moonshot Blue Ribbon Panel and NCI Acting Deputy Director Dinah Singer, PhD, Nov. 19 [published](#) a Cancer Moonshot progress report in the Cancer Currents Blog. Dr. Singer shared updates on the science being funded by the Cancer Moonshot, including research teams with various goals: one focused on immunotherapy in adults and another in children; identifying immune targets and treatments specific to pediatric cancers; implementation science to make progress in cancer prevention and early detection; and a focus on basic research.

### 3. NIH Statement on World COPD Day 2018

The NIH Nov. 20 [issued a statement](#) in conjunction with World COPD Day 2018, renewing the agency's "long-standing commitment to reducing the burden of chronic obstructive pulmonary disease ([COPD](#)), a serious and debilitating lung disease." NIH, through NHBLI, joins in multiple partnerships to find a COPD cure, including the COPD National Action Plan, the COPD Clinical Research Network, and the COPD Learn More Breathe Better program.

### 4. STAT: Chinese Researcher Claims Birth of First Gene-Edited Babies

STAT and other media outlets Nov. 25 [reported claims](#) of Chinese scientist He Jiankui, PhD, that he used the gene-editing tool CRISPR to edit human embryos, resulting in the birth of twin girls. Dr. Jiankui used CRISPR to target a cell membrane protein that allows HIV to enter cells in an effort to prevent future HIV infection. Dr. Jiankui's claims have not gone through peer review for publication in a scientific journal. In response to the reports, University of California Berkeley's Li Ka Shing Chancellor's Chair in Biomedical and Health Sciences and Professor of Biochemistry, Biophysics and Structural Biology and co-inventor of CRISPR-Cas 9 gene editing Jennifer Doudna, PhD, [released a statement](#) urging the public to put the likely "sensationalized headlines" in perspective. She continues, "It is essential that this report not cast an untoward shadow on the many important ongoing and planned clinical efforts to use CRISPR technology to treat and cure existing genetic, infectious, and common disease in adults and in children."

### 5. STAT: Launch of an Ebola Clinical Trial Draws Near

STAT [reported Nov. 12](#) on an upcoming clinical trial for Ebola patients in the Democratic Republic of the Congo (DRC). The trial will compare four treatments without placebo, including mAB 114, a monoclonal antibody regimen being developed by the NIH and DRC's National Institute of Biomedical Research. This trial has unique challenges due to local violence, its taking place in the midst of an outbreak, and the current lack of protocol standardization.

#### **6. STAT: To Catch Misconduct, Journals are Hiring Research Integrity Czars**

Also in STAT [Nov. 21](#), Ivan Oransky and Adam Marcus report on scientific publishers' hiring of scientific integrity officers, or "integrity czars" to investigate potential research misconduct before research is published. Hindawi Head of Research Integrity Matthew Hodgkinson comments, "We've always been seeing issues like plagiarism, like authorship disputes, like data fabrication. But there was a lack of awareness of the scale ... [which] reflected the realization that we need to be catching these issues as a core focus."

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

#### **7. 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**

#### **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. The Government Relations Manager will devise strategies and tactics to achieve specific policy objectives in collaboration with AHA media, grassroots and policy staff; serve on coalitions and other external working groups or organizations focused on research and prevention issues; build relationships and maintain communications with Members of Congress, Executive agency officials, and their staff. This position will also manage two external coalitions focused on research and prevention funding for heart disease and stroke.

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. As part of your work, you would also identify opportunities for high level volunteers and staff to serve as representatives of the Association on appropriate federal regulatory and oversight bodies, including advisory panels and councils. Other duties may include providing limited lobbying support on proposals related to delivery system reform, quality improvement, laboratory developed tests, and other issues.

### **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@cossa.org](mailto:jobs@cossa.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).