

## Ad Hoc Group Weekly Round Up – January 22, 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:

### [Ad Hoc Group for Medical Research @fundNIH](#)

Appropriations Committee memberships for the 116th have been announced over the last week - we look forward to continuing to work with Labor-HHS Subcmte Chairs [@RoyBlunt](#) and [@rosadelauro](#) and Ranking Members [@PattyMurray](#) and [@TomColeOK04](#) to support medical research and the [#NIH!](#)

### 1. House, Senate Committee Memberships Announced for 116th Congress

Senate Appropriations Subcommittee assignments were announced [Jan. 14](#). House [Democrat](#) and House [Republican](#) assignments to the Labor, Health and Human Services, Education, and Related Agencies Subcommittee of the Appropriations Committee were also announced. House [Democrats](#) and House [Republicans](#) were also named to the Energy and Commerce Committee subcommittees the week of Jan. 14. [Senate](#) Health, Education, Labor, and Pensions Committee members are also assigned.

### 2. NIH Researchers Set Stage for Clinical Trial for Macular Degeneration

The NIH Jan. 16 shared a [news release](#) detailing a publication from NEI researchers showing success in using human-derived induced pluripotent stem cells (iPSCs) to prevent blindness in animal models of age-related macular degeneration. According to NEI's lead researcher, these results set the stage for clinical trials to treat the human disease, in what would be "the first ever to test a stem cell-based therapy derived from induced pluripotent stem cells (iPSC) for treating a disease." [STAT News](#) covered the story with additional history of the Nobel Prize-winning iPSC technology.

### 3. Science Editorial: Why We Need Fetal Tissue Research

Sally Temple, PhD, of the Neural Stem Cell Institute, and Lawrence Goldstein, PhD, of the University of California-San Diego, in a Jan. 18 [Science editorial](#) reaffirm the importance of fetal tissue research in the face of efforts by a "vocal minority" to cut off federal funding for the research. They state, "Although research into alternatives is worthwhile, there are several aspects of fetal tissue research for which alternatives do not and will not exist." [STAT](#) Jan. 15 [reported](#) on efforts by anti-abortion groups to rebrand themselves as "pro-science" while labeling fetal tissue research as wasteful and unnecessary. The article summarizes the recent listening sessions hosted by the administration to better understand the uses and value of fetal tissue research, as well as NIH's recent announcement to dedicate up to \$20 million to study alternatives to fetal tissue research.

### 4. *NYTimes*: Chinese Researcher Using CRISPR in Embryos Likely to Face Charges

The *New York Times* [Jan. 21 reported](#) that Chinese researcher He Jiankui, PhD, is likely to face criminal charges following his reported efforts to genetically modify human embryos and implant them into female volunteers, leading to the birth of at least two children. It is also reported that the Southern University of Science and Technology has rescinded Dr. He's contract, and is canceling his teaching and research duties.

## **5. NDD United Sign-On Opportunity**

Sequestration will again become a part of the appropriations discussion as the temporary and partial relief of the Bipartisan Budget Act of 2018 expires at the end of FY 2019. In the 116th Congress, threats to nondefense discretionary programs face a steep, \$55 billion funding cliff that would reverse many of the funding gains made in the last few years.

In an effort to protect NDD programs from further cuts and to end sequestration, NDD United is circulating a sign-on letter urging lawmakers to negotiate a new budget agreement providing relief from the discretionary spending caps in FYs 2020 and 2021. The Ad Hoc Group has signed on to the letter, and we encourage individual organizations to do so as well. You can review the letter [here](#) and [complete the sign on form here](#). Deadline to sign on is Jan. 31.

## **6. NIH OBSSR Requests Input on Definition of Behavioral and Social Sciences Research**

The NIH Jan. 14 published a RFI [seeking broad community input](#) on a revised [definition](#) of behavioral and social sciences research (BSSR) for use by the Office of Behavioral and Social Sciences Research (OBSSR) in the NIH Director's Office Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) to assess and monitor NIH BSSR funding. Specifically, the NIH is requesting input and suggestions on three questions: 1) is the definition clear, 2) how well does the definition capture the full range of health-related behavioral and social sciences research at the NIH, and 3) how well does the definition distinguish behavioral and social sciences research from other disciplines of research. Responses must be submitted by Feb. 22 through OBSSR's crowdsourcing [IdeaScale website](#), where users may also view and comment on others' ideas.

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

### **7. AdvaMedDx and ACS CAN Congressional Briefing – Feb. 14**

AdvaMedDx and the American Cancer Society Cancer Action Network (ACS CAN) invite you to a congressional briefing titled "Accelerating Global Elimination of Cervical Cancer: A Call to Action." The briefing will cover how, with U.S. investment and leadership, we can accelerate the elimination of cervical cancer death globally, saving hundreds of thousands of lives. The briefing will take place from 12-1:30pm on Feb. 14 in 2017 Rayburn House Office Building. Please [RSVP by Feb. 12](#) and see attached for additional information.

### **8. NCATS Hosting its Rare Disease Day – Feb. 28**

The NIH's National Center for Advancing Translational Sciences (NCATS) with the NIH Clinical Center is hosting [Rare Disease Day](#) on Feb. 28 on the NIH campus in Bethesda, MD. The annual event is intended to raise awareness about these diseases, the people they affect, and new research opportunities through panel discussions, posters, artwork, tours, and networking

opportunities. Speakers include NIH Director Francis Collins, MD, PhD; NCATS Director Christopher Austin, MD; and NIH Clinical Center CEO James Gilman, MD. Admission is complimentary and open to the public. On February 22, NIH will host a Twitter chat on rare diseases from 1-2 PM ET featuring Drs. Collins, Austin, and Gilman as well as representatives from the rare diseases advocacy community.

#### **9. AAMC/FASEB Webinar on NAS's Next Generation of Researchers Report – Feb. 19**

The Association of American Medical Colleges (AAMC) and the Federation of American Societies for Experimental Biology (FASEB) are hosting the fourth webinar in their 2018/2019 National Academies reports [webinar series](#). Program Officer Lida Beninson, PhD, of the National Academies, will unpack the key findings of the report "[The Next Generation of Biomedical and behavioral Sciences Researchers Breaking Through](#)." The webinar is being held on Feb. 19, 1:00-2:00 PM ET and free [registration](#) is required.

### **Job Postings**

#### **NIH OSP Now Seeks Director of Science Policy, Coordination, Collaboration, and Reporting Division**

The [NIH Office of Science Policy](#) is announcing a vacancy for the Director of its Science Policy, Coordination, Collaboration, and Reporting Division. This vacancy represents an exceptional opportunity for a multi-talented individual to: establish a policy portfolio that cuts across the biomedical research enterprise, including issues such as rigor and reproducibility, public-private partnerships, and other emerging priorities; lead projects to develop the evidence base for proactive policies shaping the conduct of biomedical research; manage high profile collaborations on behalf of the NIH Director; facilitate key partnerships within NIH to ensure seamless coordination on policy issues; and build and manage a high-performing team of science policy professionals and analysts.

Please visit the links for [external](#) or [internal](#) candidates to apply.

#### **ALS Seeks Associate Director, Grassroots Advocacy**

Bring your passion and leadership to join the fight against ALS! The Associate Director, Grassroots Advocacy will report to the Vice President, Public Policy and work as part of a team with the Associate Director for Government Affairs and the Public Policy Manager. The successful candidate will design and direct nonpartisan grassroots activities, including managing an annual Fly-In and the National ALS Advocacy Conference and working with ALS chapters and volunteer leaders. While federal level advocacy is the main focus, the candidate will also develop a new program to support chapters on state level advocacy. [Apply here](#).

#### **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 visit the [job posting](#) to apply.

#### **FASEB Seeks Senior Science Policy Analyst**

The Federation of American Societies for Experimental Biology seeks a Senior Science Policy Analyst. Primary functions of the role include analyzing science policy issues and independently managing committees, projects, reports, and seminars/workshops pertaining to the training and development of the biological and biomedical workforce and other topics of concern to the sustainability of the research enterprise. Please visit FASEB's [employment opportunities](#) site for [additional information](#) and a [link to apply](#).

### **ASHG Seeks Two Policy and Advocacy Assistant**

The American Society of Human Genetics (ASHG), the primary professional membership organization for human genetics specialists worldwide, seeks a Policy & Advocacy Assistant. This person will report to the Senior Director, Policy and Advocacy, and will help fulfill the Society's advocacy role by helping to develop advocacy resources for members; supporting the development of policy statements; and coordinating policy and advocacy-related events and other administrative duties. Please visit FASEB's [employment opportunities](#) site for [additional information](#) and a [link to apply](#).

### **National MS Society Seeks Manager, Government Relations**

The National Multiple Sclerosis Society mobilizes people and resources to drive research for a cure and to address the challenges of everyone affected by MS. The Manager, Government Relations, will provide advocacy and policy support across all of the Society's activism. The position will directly lobby Congress, as well as implement advocacy and lobbying strategies and tactics at the federal and state levels. The position will be responsible for public policy and legislative research and analysis to help determine, assess and manage the Society's federal, state and local policy priorities. Additionally, the position will engage with advocacy staff and volunteers across the country. For more information and to apply, click [here](#).

### **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](#).

### **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. 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.

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).