

## Ad Hoc Group Weekly Round Up – July 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:

### [ACT for NIH Foundation @ACTforNIH](#)

China has devoted \$9.2 billion to its 15-year Precision Medicine Initiative to map 100 million human genomes—far more than the U.S. \$215 million investment targeting 1 million patients. We must [#FundNIH](#).

### 1. Negotiators Near Deal on Budget Caps, Debt Ceiling Solution

House Speaker Nancy Pelosi (D-Calif.) and Treasury Secretary Steven Mnuchin have reportedly nearly reached a two-year deal to raise budget caps and suspend the debt limit after negotiations continued the week of July 15. The Trump Administration July 18 sent Speaker Pelosi a list of \$574 billion in programs that could offset the proposed spending increases. According to [CQ](#) (subscription required) and the [Washington Post](#), approximately half of the administration's requested \$150 billion in offsets will be included in the final package. The House of Representatives will need to vote on a final spending bill by Friday, July 26, before a six week-long recess. The Senate is expected to be in session the week of July 29.

The Ad Hoc Group April 10 released a [statement](#) urging lawmakers and the administration to quickly reach consensus and raise the budget caps for FYs 2020 and 2021 to avoid “impractical spending limits that could slow our progress toward cures and impede our ability to address major public health challenges.” The House Appropriations Committee deemed a \$641 billion increase in nondefense spending to prepare its FY 2020 spending bills. The Senate has not yet drafted its FY 2020 spending bills, pending a finalized budget caps deal.

### 2. NIH Releases New Video on the “NIH Story”

The NIH released [a new video](#) that “captures the spirit, mission, community, and the lifesaving work at NIH and the more than 2,500 universities, medical schools, and other research institutions in every state and around the world.”

### 3. Members of Congress Address HHS Regarding Fetal Tissue Research

Chair of the House Committee on Oversight and Reform Elijah Cummings (D-Md.) and Ranking Member of the Senate Health, Education, Labor, and Pensions Committee Patty Murray (D-Wash.) sent a July 17 [letter](#) seeking clarification from HHS Secretary Alex Azar regarding the department's scientific rationale for the June 5 [policy](#) to limit the use of fetal tissue in research supported by the NIH. In the letter, the Members request specific information from the secretary by July 31, including documents related to the department's review of fetal tissue research, meeting records that informed development of the policy, and various communications between leadership in the department and the administration.

### 4. Senators Introduce Gene Editing Resolution

Senators Dianne Feinstein (D-Calif), Marco Rubio (R-Fla.) and Jack Reed (D-R.I.) July 15 introduced a bipartisan resolution, [S. Res. 275](#), “calling for international ethical standards in genome editing research.” The Resolution states the sponsors’ opposition to human gene-editing experiments that result in a pregnancy, supports the development of “an international framework regarding human germline editing,” and encourages international collaboration between the Secretary of State, the United Nations, and the World Health Organization to “forge an international consensus regarding the limits of ethical clinical use of genome-edited human embryos.”

#### **5. NIH Reports Largest Genomic Study on Type 2 Diabetes in Sub-Saharan African Population**

The NIH July 19 issued a [news release](#) on a newly published study of over 5,000 individuals from Nigeria, Ghana, and Kenya with type 2 diabetes. The findings from this largest diabetes genomic association study suggest that a novel gene, *ZRANB3*, could make individuals more susceptible to the disease and allow for earlier medical interventions. NIH Director Francis Collins, MD, PhD, co-authored the paper and commented, “Africa is the original cradle of all humanity, to which all humans can trace their genetic origin. Thus, studying the genomes of Africans offers important opportunities to understand genetic variation across all human populations.”

#### **6. Open Mike: Achieving Gender Equity at Conferences**

NIH Deputy Director for Extramural Research Mike Lauer, MD, July 22 authored a new [blog post](#) addressing gender equity and the need to increase diversity at scientific conferences. Dr. Lauer notes, “it is important to have diversity across many dimensions, including representation of individuals from underrepresented racial and ethnic groups, from a variety of regions and institutions, career stages, and with disabilities ... it’s about changing the fundamental culture of the biomedical research enterprise.”

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

#### **7. NIH Caucus Congressional Briefing – July 24**

Please join the Congressional NIH Caucus for a briefing titled, “The NIH BRAIN Initiative: Revolutionizing Our Understanding of the Human Brain.” The briefing will take place Wednesday, July 24, from 12:00-1:30pm in 485 Russell Senate Office Building. Please see attached flyer for more information and RSVP to [RSVP@ACTforNIHFoundation.org](mailto:RSVP@ACTforNIHFoundation.org).

#### **8. NASEM Meeting on Clinical Use of Human Genome Editing – August 13**

The National Academies of Sciences, Engineering, and Medicine (NASEM) is hosting the [first meeting](#) of the International Commission on Clinical Use of Heritable Human Genome Editing from 8:30 am – 5:15pm on August 13 in Washington, D.C. This goal of this commission is to “develop a framework for scientists, clinicians, and regulatory authorities to consider when assessing potential clinical applications of human germline genome editing...if society concludes that heritable human genome editing applications are acceptable.” [Registration](#) is required to attend the event in person or to view the webcast.

#### **9. Rally for Medical Research – September 18-19**

Join a broad coalition of stakeholders representing millions of patients and other advocates from the medical research advocacy community on September 18-19, 2019, for the next Rally for

Medical Research Hill Day and help raise awareness of the urgent need for continued investment in the NIH to improve health, spur more progress, inspire more hope, and save more lives. Please visit the [event website](#) for more information and to register. Registration closes August 30.

#### **10. NIH Fall Regional Seminar – Nov. 6-8**

The NIH is hosting the Fall 2019 NIH Regional Seminar on Program Funding and Grants Administration in Phoenix, AZ, from Wednesday, Nov. 6- Friday Nov. 8. Visit the [website](#) to learn more about the program and to [register](#). Early registration rates apply through June 30.

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).