

Ad Hoc Group Weekly Round Up – September 3, 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:

[AdHocGrp for Med Res @fundNIH](#)

Aug. 17 - Today marks 10 yrs w/ Dr. Francis Collins leading [#NIH](#), the world's premier research agency! [@NIHDirector](#), thank you for your dedicated service, inspiring researchers to discover lifesaving treatments and improving the lives of all Americans.

<https://aamc.org/research/adhocgp/08.17.19CollinsLetter.pdf>

1. FY 2020 Senate Appropriations September Outlook

According to press reports, Senate Appropriations Chair Richard Shelby (R-Ala.) the week of August 5 provided Senate committee staff with 302(b) allocations for all 12 FY 2020 spending bills. Prior to the start of Congress's August recess, the Senate Labor-HHS spending bill markup was expected the week of September 9 but it is unclear whether a markup has been officially scheduled. Additionally, Sen. Shelby noted after the August 1 passage of the Bipartisan Budget Agreement that a bicameral agreement and passage of all spending bills by the end of the fiscal year on September 30 was a challenging goal to meet.

2. Administration Releases FY 2021 R&D Budget Priorities

OMB Acting Director Russell Vought and OSTP Director Kelvin Droegemeier, PhD, August 30 [released a memo titled](#), "Fiscal Year 2021 Administration Research and Development Budget Priorities." The guidance includes five R&D budgetary priorities and five crosscutting actions that span all priorities. Under the American Health & Bioeconomic Innovation priority area, the memo includes the biomedicine priorities of "combatting the opioid crisis, rapid detection and containment of infectious diseases, anti-microbial resistance, chronic disease prevention and treatment, gene therapy, neuroscience, medical countermeasures and public health preparedness, eradicating HIV/AIDS once and for all, and enhancing the independence, safety, and wellness of aging Americans and individual with disabilities."

3. *Open Mike*: How Institutions Can Promote a Culture of Research Integrity

In an August 15 [Open Mike blog post](#), NIH Deputy Director for Extramural Research Mike Lauer, MD, conveys his thoughts on how institutions can foster a culture of research integrity based on his presentation at a May 22 conference on research integrity. The presentation covered topics such as vocabulary to describe research misconduct; recommendations for academic thought leaders; the importance of communication and information-sharing; and suggested policies for institutions and the government.

4. *All of Us* Research Program Progress Report and Leadership Changes

Leadership from NIH's *All of Us* Research Program August 15 [published a progress report](#) in the *New England Journal of Medicine* with corresponding [NIH media advisory](#). The program reports over 230,000 enrollees, with 80% from "groups that have been historically underrepresented in biomedical research." The authors note that continued success will rely on

participation by diverse enrollees who will remain engaged with the program, as well as constant monitoring of cybersecurity and data privacy integrity. The research program [August 21 also announced](#) a \$4.6 million award to the health technology company Color “to establish the program’s nationwide genetic counseling resource” for program participants.

In a separate statement, *All of Us* director Eric Dishman, MS, [August 27 announced](#) that he will step down from the role of director and transition to be the program’s Chief Innovation Officer once his replacement is announced.

5. NIH Issues Clarifying Guide Notice on Fetal Tissue Research

The NIH August 23 [released a notice](#), Clarifying Competing Application Instructions and Notice of Publication of Frequently Asked Questions (FAQs) Regarding Proposed Human Fetal Tissue Research. The notice offers additional clarification to its [July 26 notice](#) of specific changes to competing grant and cooperative agreement application instructions. This follows HHS’s [June 5th announcement](#) of policy and regulatory changes regarding research with fetal tissue from an elective abortion.

6. National Academies Issues Report on Funding Needs for NIH Infrastructure

The National Academies of Sciences, Engineering, and Medicine [August 26 issued a report](#) on the NIH campus infrastructure titled, “Managing the NIH Bethesda Campus’s Capital Assets for Success in a Highly Competitive Global Biomedical Research Environment.” The report, in response to a 2017 Congressional request, recommends that Congress provide “\$1.3 billion in new funding to address the Bethesda Campus’s needs to upgrade its buildings and facilities.”

7. Myositis Association, University of Pittsburgh Launch Myositis Trial Funded by NIH

The Myositis Association (TMA) is partnering with University of Pittsburgh for a new NIH-sponsored study titled, “Myositis Patient Centered Tele-Research (My-PACER).” The investigators of this study have a long-standing interest in myositis. Patients with polymyositis (PM), dermatomyositis (DM), or necrotizing myopathy (NM) may be able to participate in this observational research study to help find innovative ways to conduct research in rare diseases like myositis, which may help in finding effective therapies in future. Please share with your patients. For more information, please go to [TMA’s blog](#).

8. International Commission on Gene Editing Holds First Meeting

The International Commission on the Clinical Use of Human Germline Genome Editing, convened by the National Academy of Medicine, National Academy of Sciences, and the UK Royal Society, August 13 [held its first meeting](#). The purpose of the Commission is to “develop a framework for scientists, clinicians, and regulatory authorities to consider when assessing potential clinical applications of human germline genome editing.” No guidelines were developed during the first meeting, and commission plans to release a final report in spring of 2020.

Upcoming Hill Briefings and Other Events

9. Golden Goose Award Ceremony – September 10

Save the date! The 8th annual Golden Goose Awards will be held September 10 at 5:30pm at the Library of Congress. This award celebrates federally funded research that may be odd,

obscure, or serendipitous but ends up having a major impact on society. Visit the [event website](#) for additional information.

10. Congressional Briefing – The Future of Cancer Immunotherapy – September 11

Please join the Coalition for the Life Sciences as they host a Congressional briefing titled, “The Future of Cancer Immunotherapy,” featuring Nobel Laureate Dr. James Allison. The briefing will be held Wednesday, September 11, from 12:00-1:00pm in 2043 Rayburn House Office Building. Please see the event flyer for additional details, and RSVP to cls@coalitionforlifesciences.org.

11. Emerging Vision Scientists Day Briefing and Reception – September 18

Please join the Alliance for Eye and Vision Research (AEVR) as they host two events for Emerging Vision Scientists Day. A Congressional briefing titled, “New Stem Cell-Based Therapies for Age-Related Macular Degeneration and Blast-Related Eye Injuries,” will take place on Wednesday, September 18, from 12:00-1:15pm in 2043 Rayburn House Office Building.

AEVR will also host an evening reception featuring early-stage vision investigators from 5:30-7:30pm in the Rayburn House Office Building Foyer. Please see attached flyers for additional details, and RSVP for both events to Dina Beaumont @ 202-407-8325 or dinabeau@aol.com.

12. 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 September 4.

13. 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](#).

Job Postings

FASEB Seeks Diversity, Equity, and Inclusion Manager

The Federation of American Societies for Experimental Biology (FASEB) seeks an experienced professional to serve as Manager, Diversity, Equity, and Inclusion (DEI) initiatives. The successful candidate will work across the FASEB departments and 29 member societies to implement FASEB’s DEI Strategic Plan and the efforts of the DEI Committee. The DEI Manager will also play a critical role in outreach by establishing collaborations with FASEB member societies and related stakeholder organizations and contributing to FASEB communications activities. The position incorporates opportunities for highlighting DEI initiatives in FASEB's broader advocacy and policy efforts. More details are in the [position description](#) and the [application site](#).

FASEB Seeks Science Policy Analyst

The Federation of American Societies for Experimental Biology seeks a Science Policy Analyst to spearhead its efforts related to research workforce and career development. Excellent opportunity for someone transitioning from bench to Beltway! Please see the complete [position description](#), and visit <https://bit.ly/2Sefl0u> or email a cover letter, CV/resume, and policy-oriented writing sample to resumes@faseb.org to apply.

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 or Tannaz Rasouli at trasouli@aamc.org.