

Ad Hoc Group Weekly Round Up – August 20, 2018

Editor's Note: Anticipating that both the House and Senate will be in August recess the week of August 27, the Ad Hoc Round Up will take a one week hiatus on August 27, and will resume publication after Labor Day!

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 Institutes of Health [@NIH](#)

A year ago, 14-year-old Rohith Lokesh spent most of his days in pain & unable to walk. Today, he's winning dance contests, thanks to [@genome_gov](#) researchers. Rohith is one of the many people helped by transformative treatments developed at [#NIH](#). [#ThisIsNIH](#)
<http://bit.ly/2ORmXUP>

1. Appropriations Update

The Senate August 15 officially agreed to begin consideration of the FY 2019 Labor-HHS-Education spending bill as Division B of a package with the chamber's FY 2019 Defense appropriations bill (Division A), using the House-passed Defense spending bill ([H.R. 6157](#)) as the vehicle for the "minibus." The bulk of the debate will occur the week of Aug. 20. The Ad Hoc Group sent an [Aug. 16 letter](#) encouraging all senators to support the spending bill's "strong investment" of at least \$39.1 billion for NIH and to continue the Senate Appropriations Committee's bipartisan approach.

The White House issued an Aug. 15 [Statement of Administration Policy](#) (SAP) criticizing that the non-defense spending in the bill exceeds the levels proposed in the president's FY 2019 budget request. The SAP also expresses disappointment over other deviations from the president's proposal, including the request to consolidate three agencies within the NIH, among other policies (see pg. 5 of the SAP), echoing sentiments the White House expressed to appropriators in a [July 16 letter](#) on the spending bill.

2. Senate HELP Committee Hearing on Prioritizing Cures – August 23

NIH Director Francis Collins, MD, PhD, is scheduled to testify before the Senate HELP Committee at an [Aug. 23 hearing](#) titled, "Prioritizing Cures: Science and Stewardship at the National Institutes of Health." The hearing is scheduled for 10 a.m. in 430 Dirksen Senate Office Building.

3. NIH Proposes to Streamline Review of Gene Therapy Trials

The NIH August 16 issued a [Federal Register notice](#) seeking comment on a proposal to amend the [NIH Guidelines for Research Involving Recombinant or Synthetic Nucleic Acid Molecules](#). The proposal seeks to "streamline oversight for human gene transfer clinical research protocols and reduce duplicative reporting requirements already captured within the existing regulatory framework." Additional information on the proposal is included in: an August 15 [New England Journal of Medicine Perspective](#) co-authored by NIH Director Francis Collins, MD, PhD and FDA Commissioner Scott Gottlieb, MD; Dr. Collins' August 16 [statement](#); and in an August 16

[blog post](#) by Acting NIH Chief of Staff and Associate Director of Science Policy, Carrie Wolinetz, PhD. Comments are due October 16, 2018.

4. NIH RFI: Reporting Standards for Basic Science Studies Involving Human Participants

The NIH August 10 issued a [Request for Information \(RFI\)](#) on "the standards NIH should use in assuring adequate registration and results information reporting for fundamental research studies involving human participants." The NIH is "considering prospective basic science studies involving human participants to be those that overlap with both the definition of fundamental research and the definition of a clinical trial" and is requesting input on several topics covered in the RFI. NIH Deputy Director of Extramural Research Mike Lauer, MD, discusses the RFI further in an August 16 Open Mike [blog post](#). The deadline to respond is November 12.

5. NIH begins clinical trial of live, attenuated Zika vaccine

The NIH [reported](#) August 16 that "vaccinations have begun in a first-in-human trial of an experimental live, attenuated Zika virus vaccine developed by scientists at the National Institute of Allergy and Infectious Diseases (NIAID)." Phase 1 of clinical testing enrolled 28 healthy adults to "analyze [the immune] response in participants and assess the safety of the experimental vaccine" and is expected to take approximately one year to complete.

6. Updates on NIH Extramural Research Website

The NIH recently posted several updates to the Extramural Nexus site. The human subjects and clinical trial glossary has been [updated](#), and the main page now contains a [visual overview](#) of the human subjects system. A [new FAQ](#) has been posted for Clinical Trial K applications. And, the NIH provided [an explanation](#) as to whether studies ancillary to clinical trials should be considered clinical trials as well.

7. Senate NIH Caucus – Ask Senators to Join!

The Senate NIH Caucus co-chaired by Senator Lindsey Graham (R-SC) and Senator Richard Durbin (D-IL) currently has 20 members. During August recess, grassroots advocates will have the perfect opportunity to ask their senators to join the NIH Caucus (see attached NIH Caucus flyer for the list of members). The Caucus promotes the need for sustained, predictable investment in biomedical research funded by the National Institutes of Health and the importance of treating and curing disease, securing our nation's global competitiveness, protecting us from bioterrorism, and boosting the economy. Please see attached flyer for additional details.

Upcoming Hill Briefings and Events

8. NASEM: Upcoming Meeting and Webinar on Preventing Sexual Harassment in Academia

The National Academies of Science, Engineering, and Medicine (NASEM) will be hosting [a webinar](#) on August 30, 1:00 - 2:00 PM ET, led by two members of the authoring committee of the [recent report](#) "Sexual Harassment of Women: Climate, Culture, and Consequences in Academic Science, Engineering, and Medicine." report, to discuss why addressing

organizational climate is important to preventing sexual harassment and how certain policies and strategies recommended in the report can be applied in academia and industry to prevent sexual harassment. Free registration is required.

Additionally, NASEM is [convening leaders](#) including “academic leaders, Title IX and diversity officers, ombudsmen, researchers in sexual harassment, and leaders from professional societies, foundations, and federal agencies to discuss strategies and share promising practices” to continue the discussion. The meeting, being held on November 9, 2018, from 9:00am – 5:00pm in Washington DC, and will focus on developing strategies on how to prevent sexual harassment in academia.

9. NIH Council of Councils Meeting – September 7

Through a Federal Register [notice](#), the NIH announced a meeting of the Council of Councils, scheduled for September 7. Agenda items include announcements and updates; Environmental influences on Child Health Outcomes (ECHO); All of Us Program Update; NIH Update; Common Fund Program – Stimulating Peripheral Activity to Address Conditions; and Workshop Report on Contributions of Social and Behavioral Research in Addressing the Opioid Crisis. The meeting will take place at NIH campus, 9000 Rockville Pike, Building 60/Cloisters, Lecture Hall/Chapel, Bethesda, MD 20892.

10. NIH Workshop on Single IRB Resource and Infrastructure Development – September 12

The NIH will be holding a [public workshop](#) on "successful strategies and lessons learned for modifying and enhancing institutional IRB infrastructure for single IRB review of multi-site studies" on September 12 in Rockville, MD. The seven awardees of the NIH-funded [administrative supplements](#) to develop applicable approaches to single IRB review of multi-site studies will present their strategies at the workshop. The meeting is free and will be webcast, but seating is limited, and registration is required.

11. Coalition for Health Funding 3rd Annual Public Health Fair – September 12

On behalf of the Coalition for Health Funding, you are cordially invited to the Third Annual Public Health Fair on September 12 from 12:00pm – 3:00pm. The Public Health Fair will feature representatives from 37 national health organizations and federal health agencies who are working in concert to improve America's health and well-being. This unique event will provide the opportunity to learn more about the full breadth of federally-funded public health and health research programs - from bench to bedside to curbside and beyond - and how these initiatives are helping Americans lead healthier, more prosperous lives across their lifespan. The Fair will take place in the Rayburn Atrium, Rayburn House Office Building. To view the event flyer, click [here](#).

12. Rally for Medical Research – September 12-13

Join a broad coalition of stakeholders representing millions of patients and other advocates from the medical research advocacy community on September 12-13, 2018, 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 see attached flyer or visit the [event website](#) for more information and to register.

13. AEVR Hill Briefing on Age-Related Macular Degeneration – September 27

Please join the Alliance for Eye and Vision Research (AEVR) for a Hill briefing titled, “Understanding the ‘Dry’ Form of Age-Related Macular Degeneration (AMD) To Develop Effective Treatments.” The event will take place September 27 from 12-1:15pm in 2060 Rayburn House Office Building. Please RSVP to dinabeau@aol.com and see the attached flyer for additional information.

14. AEVR 25th Anniversary Reception – September 27

Please join AEVR for its 25th Anniversary celebration and poster session, including 21 Emerging Vision Scientists in the U.S. The reception will be held on September 27 from 5:30-7:30pm in the Rayburn House Foyer. Please RSVP to dinabeau@aol.com and see the attached flyer for additional details.

15. Call for Golden Goose Award Nominations

The Golden Goose Award team is accepting nominations for the 2018 year. The Golden Goose Awards honor federally funded research that may be odd, obscure, or serendipitous but ends up having a major impact on society. To submit a nomination, [follow this link](#), or visit goldengooseaward.org and click on “nominate” in the top right corner. If submitting a nomination, be prepared to talk about who you are nominating, what unexpected impact the research has had, and which U.S. federal agency funded the work. Nominations are accepted on a rolling basis throughout the year.

16. Learn Serve Lead – November 2-6, 2018

Learn Serve Lead 2018 - the AAMC Annual Meeting is open for registration. The November 2-6 event takes place in Austin, Texas and will draw 4500-plus attendees including a wide range of stakeholders. In addition to [four plenary sessions](#) including Grit author and researcher Angela Duckworth, PhD, and civil and women’s rights leader Anita Hill, JD, there are more than 130 concurrent sessions. Some of the slated sessions include:

- Improving Population Health Through Learner-Engaged Research
- Rightsizing Research Infrastructure
- Achieving Health Equity through Research: Innovations From NIMHD-Funded Science
- Unhealthy Politics: The Battle over Evidence-Based Medicine

[Discounted registration](#) is available through August 31.

Job Postings

FASEB Seeks Science Policy Analyst

The Federation of American Societies for Experimental Biology (FASEB) is hiring a [Science Policy Analyst](#) to develop policy positions related to promoting the interests of investigators in the biological and biomedical sciences. The individual will write position statements, meeting summaries, and reports and serve as a liaison to FASEB Science Policy Subcommittees and task forces, in addition to monitoring the Federal Register and attending federal agency meetings. The position is full time, includes benefits, and is located at FASEB headquarters in Bethesda, MD. PhD preferred. Interested applicants can [apply online](#).