

Ad Hoc Group Weekly Round Up – July 23, 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:

The Association for Research in Vision and Ophthalmology, [@ARVOinfo](#)

“Why [#fundNIH](#)? Because funding enabled Cynthia Toth, MD, of [@dukeeyecenter](#) to develop a technology that catches preemie eye disease early enough to save sight. <http://www.arvo.org/oct> [#OCTImaging](#) [@NatEyeInstitute](#) [#EyeSummit](#)”

1. Appropriations Update

The week of July 23, the full Senate is expected to take up the FY 2019 Interior-Environment and Financial Services appropriations bills, passed July 19 in the House. Reports suggest that the Senate may also add the Senate Appropriations Committee-passed Agriculture and Transportation and Housing and Urban Development bills to the final package. With passage of these four bills, the Senate may move on to a two bill package including the Labor-HHS and Defense bills as early as the week of July 30.

2. House Energy & Commerce Hearing on 21st Century Cures Implementation

The House Energy & Commerce Committee July 25 [will hold](#) a hearing titled, “21st Century Cures Implementation: Updates from FDA and NIH.” NIH Director Francis Collins, MD, PhD, and FDA Commissioner Scott Gottlieb, MD, will testify. The Committee's [background memo](#) outlines the two agencies' relevant programs of jurisdiction under the law, including the Precision Medicine Initiative, the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, the Cancer Moonshot, and the Regenerative Medicine Innovation Project at NIH.

3. NIH Director Discusses HEAL Initiative on Federal News Radio

NIH Director Francis Collins, MD, PhD, July 20 [conducted an interview](#) on the Federal News Radio to discuss the NIH's HEAL (Helping to End Addiction Long-term) Initiative. The interview focuses on the \$500 million set aside for the program in the FY 2018 appropriation, including plans for both research and active outreach under the initiative.

4. OHRP Announces Draft Guidance on Three Burden-reducing Provisions of the Revised Common Rule

The Office of Human Research Protections (OHRP) July 20 posted [three draft guidance documents](#) on burden-reducing provisions of the [revised Common Rule](#) in recognition of the general compliance delay period, which began July 19. Institutions may choose to implement these three burden-reducing provisions before the implementation date, January 21, 2019, but in doing so, they will have committed to following the entire revised Common Rule for ongoing projects. OHRP will be publishing a Federal Register Notice of Availability (NOA) about these draft guidance documents soon and will solicit comments within 30 days of that publication.

5. NIH Posts Notice on Basic Science Studies Involving Human Participants

Relating to the [NIH clinical trials](#) policies, the NIH July 20 posted [a notice](#) on "Delayed Enforcement and Short-Term Flexibilities for Some Requirements Affecting Prospective Basic Science Studies Involving Human Participants." The notice states that: "Based on the 2018 appropriations bill and community feedback, NIH is delaying enforcement of registration and reporting policies for prospective basic science studies involving human participants under [NOT-OD-16-149](#) through September 24, 2019. The delayed enforcement of registration and reporting is only applicable for prospective basic science studies that involve human participants. These studies do not include those for which there are specific applications towards products or processes in mind, such as phase 0 or phase 1 studies of candidate interventions." The NIH plans to collect more feedback from the community through a Request for Information and to publish new Funding Opportunity Announcements in the fall for research in this category.

6. PNAS: NIH Funding Longevity by Gender

A [study](#) published by NIH's National Institute of General Medical Sciences (NIGMS) staff in the Proceedings of the National Academy of Sciences (PNAS) determined that once women receive their first NIH grant, they are just as likely as men to remain funded. The authors note that only 31% of the grantees in their study were women, suggesting that "efforts may be best directed toward encouraging women to enter academia and supporting their continued grant submissions." The study is also covered in a July 16 [Science](#) article, and in an NIGMS Feedback Loop [blog](#).

7. Updated Notice of NIH's Interest in Diversity

The NIH updated its [Notice of NIH's Interest in Diversity](#) to include recent data on which populations are underrepresented in the U.S. biomedical, clinical, behavioral and social sciences research enterprise. The notice emphasizes that women from backgrounds underrepresented in research "face particular challenges at the graduate level and beyond in scientific fields" and encourages "institutions to consider women for faculty-level, diversity-targeted programs to address faculty recruitment, appointment, retention or advancement."

8. NAS Report: Open Science by Design

The National Academy of Sciences released [a report](#) titled "Open Science by Design", which states that "the global research enterprise and its stakeholders are moving toward a new open science ecosystem." An Inside Higher Ed [article](#) explains that the report includes recommendations to "include creating better rewards for academics who practice open science, incorporating open science training into student curricula and making it easier for researchers to identify which research materials should be preserved and shared."

9. NIH Launches Largest Coordinated Research Program on Prostate Cancer

The NIH, in collaboration with the Prostate Cancer Foundation (PCF) July 17 [announced](#) a collaborative research program, Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers, and Social Stress (RESPOND), to study aggressive prostate cancer in African-American men. The article cites that "African-American men have about a 15 percent chance of developing prostate cancer in their lifetimes, compared to about a 10 percent chance for white men, and African-American men are more likely to be diagnosed with aggressive disease." The study hopes to enroll 10,000 male volunteers and use

cutting-edge molecular, social, and environmental science tools to better understand the higher prostate cancer rates.

10. STAT: New Study Shows Higher Rates of DNA Damage in CRISPR Research

A July 16 story in [STAT](#) describes new research suggesting that CRISPR may be producing more DNA damage than previously thought. The original research published in [Nature Biotechnology](#) suggests that CRISPR may induce large scale deletions both close to and far from the genomic target, some of which can “silence genes that should be active and activate genes that should be silent, including cancer-causing genes.” This result has implications for the future of CRISPR-based therapy for certain genetic diseases. One [NIH-funded clinical trial](#) using CRISPR in T cells is already underway for the treatment of four distinct cancers.

11. Senate NIH Caucus Updates

The Senate NIH Caucus was launched on May 19, 2015, by co-chairs Senator Lindsey Graham (R-SC) and Senator Richard Durbin (D-IL). The NIH Caucus promotes the need for sustained, predictable investment in biomedical research funded by the National Institutes of Health and the value it adds to the country in treating and curing disease, securing our nation’s global competitiveness, protecting us from bioterrorism, and boosting the economy. Ask your Senators to join the NIH Caucus to show their support for the groundbreaking research done at universities and institutions across the country. See attached flyer for a list of current caucus members.

Upcoming Hill Briefings and Events

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. Registration Open for NIH Workshop on Single IRB Resource and Infrastructure Development

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.

14. 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.

15. 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](#).

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.