



THE AD HOC GROUP FOR MEDICAL RESEARCH

Ad Hoc Group Weekly Round Up

March 9, 2020

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:

Senator Chris Van Hollen [@ChrisVanHollen](#) March 6

After voting for the \$8.3 billion plan to combat the coronavirus, [@RepRaskin](#), [@SenatorCardin](#), and I visited [@NIH](#) to hear from the scientists who are on the front lines. NIH is a national treasure and we must ensure they have the resources they need to protect the public health.

President Signs Coronavirus Supplemental Funding Package

President Trump signed into law a supplemental spending package on March 6 to help combat the coronavirus, following the bill's passage in the House of Representatives on March 4 and in the Senate on March 5 by votes of [415-2](#) and [96-1](#), respectively. The Coronavirus Preparedness and Response Supplemental Appropriations Act of 2020 ([HR 6074](#)) provides \$7.8 billion in new emergency funding, including \$836 million in vaccine research and development at NIH, and eases certain telehealth requirements while the coronavirus emergency declaration is active.

NIH Leadership Testifies on FY 2021 Budget Request, Coronavirus

Leaders from the NIH testified on March 4 before the [House Appropriations Subcommittee on Labor-HHS](#) to testify on the president's FY 2021 budget proposal and provide updates on the novel coronavirus (COVID-19). [NIH Director Francis Collins, MD, PhD](#), highlighted advances in gene therapies for various diseases, artificial intelligence, development of a universal flu vaccine, and progress to combat substance use disorder and addiction. National Institute of Allergy and Infectious Diseases Director Anthony Fauci, MD, noted that the research on basic virology, as well as the rapid sequencing of COVID-19, comes from NIH and its grantees.

In their opening remarks, subcommittee Chair Rosa DeLauro (D-Conn.) and Ranking Member Tom Cole (R-Okla.) pointed to the continued bipartisan support for medical research and emphasized the importance of maintaining a consistent funding growth trajectory for NIH. Full Committee Chair Nita Lowey (D-N.Y.), in what she described as likely her last NIH hearing before her retirement from Congress, criticized the "disastrous" budget request and added that "every penny" of FY 2020 funding for NIH was worth it.

Op-Ed: Impressive Leaps in Science Shown in Coronavirus Response

The Editorial Board of the *Washington Post* authored a [March 7 op-ed](#) highlighting some of the “impressive” new scientific developments that have emerged as the world responds to the ongoing COVID-19 epidemic. The board highlighted the speed and transparency of biomedical science including next-generation sequencing efficiency and NIH-funded research using cryo-electron microscopy to image the mechanism used by the virus to anchor to human cells.

CRISPR Used to Edit Inside a Patient to Combat Rare Genetic Blindness

For the first time, CRISPR gene editing technology has been used directly inside of a patient in hopes of fixing a rare genetic mutation causing Leber congenital amaurosis, which causes blindness. NIH Director Francis Collins, MD, PhD, shared in [an interview with NPR](#) that the trial and advance to editing directly in a patient is “a significant moment” and provides hope for many other diseases.

Resource on Impact of NINDS-Funded Research

The National Institute of Neurological Disorders and Stroke [maintains a resource](#) highlighting NINDS contributions to approved therapies by describing an overview of the therapy, a history and timeline of its development and NINDS’s contribution, and a list of relevant references. The latest addition to the collection highlights NINDS’s role in [optimizing endovascular therapy for ischemic stroke](#).

Upcoming Hill Briefings and Other Events

NEW NIH Hosts Webinar on Next NIH-Wide Strategic Plan – March 16

NIH has scheduled an upcoming webinar for stakeholders to learn more and ask questions about the agency’s upcoming strategic planning process. The webinar will be held on [March 16 from 10:00-11:00am EST](#). Advanced registration is required.

NEW Congressional Briefing on the Clinical Treatment Act - March 11

The Association for Clinical Oncology (ASCO) is hosting a Capitol Hill on Wednesday, March 11 from 11:00-12:00pm in the Capitol Visitor’s Center (HVC 200) on the CLINICAL TREATMENT Act ([H.R. 913](#)), which would require Medicaid to cover routine care costs for patients with life-threatening conditions on clinical trials. The panel will include a physician from ASCO, a researcher and patient advocate from the American Cancer Society Cancer Action Network (ACS CAN) and bill leads, Rep. Ben Ray Lujan (D-N.M.) and Gus Bilirakis (R-Fla.) are both expected to make remarks on this critical legislation. Please [RSVP here](#) and see the [attached flyer](#) for additional information.

Social Science Advocacy Day – March 30-31

Please join the Consortium of Social Science Associations (COSSA) as they hold their annual, coordinated advocacy day in support of all of the social and behavioral sciences. Social Science Advocacy Day brings together social scientists and other science advocates from across the country to engage with policymakers in Washington, DC. The two-day event includes in-depth training and logistical support (including scheduling meetings with Congressional offices and providing an on-call expert to answer your day-of policy questions), as well as polished, up-to-date materials to help you bring your message to Capitol Hill. [Visit the event website for more information and to register.](#)

NIH Regional Seminar in Baltimore, MD: April 20-22, 2020

The NIH is hosting the Spring 2020 NIH Regional Seminar on Program Funding and Grants Administration in Baltimore, MD, from April 20-22. [Visit the meeting website](#) to learn more about the program and to register; early bird registration rates apply through December 31.

Requests for Public Comment

DEADLINE EXTENDED Request for Public Comment on Characteristics of Data Repositories – March 17

The White House Office of Science and Technology Policy (OSTP) has issued a request for information (RFI) on characteristics of data repositories, on behalf of the multi-agency Subcommittee on Open Science of the National Science and Technology Council's Committee on Science. The proposed set of desirable characteristics for data repositories is part of the Subcommittee's efforts to improve the consistency of information that Federal agencies provide to the scientific community about the long-term preservation of data resulting from Federally funded research. Please visit the [Federal Register post](#) for more information and to submit comments by the new March 17 deadline.

NEW NINDS Seeks Feedback on Strategic Planning Process

The National Institute of Neurological Disorders and Stroke (NINDS) is embarking on an institute-wide strategic planning process, and published a [July 2019 request for information](#) on the process. The goal of the process is to tune its practices and policies to its vision and mission, in order to better serve and anticipate the needs of the research and patient communities and the public. The mission of NINDS is to seek fundamental knowledge about the brain and nervous system and to use that knowledge to reduce the burden of neurological disease. Those interested in submitting comments for consideration as NINDS establishes a new strategic plan may still do so [through this form](#).

NLM Requesting Information on ClinicalTrials.gov Modernization – March 14

The NIH's [National Library of Medicine \(NLM\) is requesting comments](#) on its multi-year plans to modernize [ClinicalTrials.gov](#), which "enhances transparency across the clinical research enterprise" and "helps enhance public trust in clinical research." The modernization initiative aims to "update the technological infrastructure underlying ClinicalTrials.gov, enhance its public-facing components, and deliver a modern user experience with a platform and services that continue to accommodate growth and enhance efficiency." Comments must be submitted electronically by March 14. Additionally, NLM will host a public meeting on April 30 to elicit further comments.

DEADLINE EXTENDED OSTP Requests Information on Public Access to Publications, Data – March 16

The White House Office of Science and Technology Policy (OSTP) is [requesting information](#) on public access to peer-reviewed scholarly publications, data, and code resulting from federally funded research. This request is part of the OSTP and the National Science and Technology Council's efforts to facilitate implementation and compliance with the 2013 [memorandum](#) on Increasing Access to the Results of Federally Funded Scientific Research and to address recommended actions made by the

Government Accountability Office in a 2019 report. Comments must be submitted by the new date of April 6.

NIH Seeks Feedback on NIH-Wide Strategic Plan – March 25

NIH has issued a [Request for Information](#) seeking public input on a framework for the 2021-2025 NIH-Wide Strategic Plan. The new plan will build on the [previous NIH-wide Strategic Plan](#) to guide NIH's research efforts over the next five years. NIH is encouraging stakeholder organizations (e.g., patient advocacy groups, professional societies, etc.) to submit a single response reflective of the views of the organization/membership as a whole. NIH will be hosting two webinars in March to describe the planning process and answer questions. Information about these webinars will be posted on the [NIH-Wide Strategic Plan webpage](#) as soon as information is available. Please provide your feedback via the [RFI submission site](#). The RFI will remain open through March 25.

NIH RFI: Priorities for Behavioral and Social Science Research – March 29

The NIH's Office of Behavioral and Social Sciences Research (OBSSR) is [requesting information](#) on its scientific priorities, particularly for three research directions that are trans-disease and cross-cutting in nature and address critical gaps in the field: synergy in basic and applied BSSR; BSSR resources, methods, and measures; and adoption of effective BSSR in practice. Comments must be submitted online by March 29.

Job Postings

NEW ASM Seeks Senior Grassroots Manager

The American Society for Microbiology is seeking a Senior Grassroots Manager. This newly created position is responsible for developing and implementing an organizational grassroots strategy to engage ASM members on public policy issues that affect the microbial sciences. Learn more and [apply here](#).

AAI Seeks Science Policy Analyst

The American Association of Immunologists (AAI), a non-profit professional biomedical research association, seeks a motivated and intellectually inquisitive individual to provide scientific expertise to the AAI public affairs program. This position supports the Director of Public Policy and Government Affairs, the members of the AAI Committee on Public Affairs, and other AAI staff in developing scientific and policy positions that convey the views, concerns, and interests of the AAI membership. Qualified candidates should submit a cover letter with resume, including publications, and salary requirements, to FASEB Human Resources at resumes@faseb.org, or visit the [FASEB employment website](#) to apply. [See attached](#) and the FASEB job site to view a detailed job description.

March of Dimes Seeks Associate Director, Maternal Health Coalition

March of Dimes is seeking an [Associate Director, Maternal Health Coalition](#) to manage March of Dimes' efforts in serving as the "backbone organization" for the Coalition for Optimal and Equitable Maternal Health, a multi-stakeholder coalition to advance maternal health. The Project Director will lead efforts to ensure the Coalition's governance through strong coalition management and support of its policy development and advocacy, data and research, and communications and outreach efforts.

ASBMB Seeks Federal Affairs Manager

The American Society for Biochemistry and Molecular Biology (ASBMB) seeks a Manager, Federal Affairs to join the Public Affairs team. The federal manager will assist in the development and execution of ASBMB public affairs programs with respect to federal science funding agencies; help manage Public Affairs Advisory Committee operations, and work closely with ASBMB public affairs leadership in developing, articulating, communicating and implementing public policy positions on behalf of ASBMB. Visit the [posting of the full job description](#) to learn more and review application instructions.

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.*