



## THE AD HOC GROUP FOR MEDICAL RESEARCH

### Ad Hoc Group Weekly Round Up

March 2, 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:

#### **National Organization for Rare Disorders [@RareDiseases](#) February 29**

It's [#RareDiseaseDay!](#) NORD is sharing stories from patients in honor of this day to raise awareness for [#rarediseases](#). Ashlee is a [#primaryimmunodeficiency](#) patient who wants to advocate for better healthcare experiences for patients. More: [bit.ly/2Vylqby](https://bit.ly/2Vylqby) [#ShowYourStripes](#)

#### **Azar Testifies on FY 2021 Budget**

Secretary of Health and Human Services Alex Azar testified before both [House](#) and [Senate](#) Labor-HHS Appropriations Subcommittees the week of February 24. Members from both chambers expressed concern regarding the administration's proposed cuts to the NIH, with chairs and ranking members from both subcommittees noting that Congress is unlikely to cut NIH funding in FY 2021.

#### **NIH Leadership to Testify on FY 2021 Budget Request**

The House Labor-HHS Appropriations Subcommittee will host NIH Director Francis Collins, MD, PhD, to testify on the administration's budget request on [Wednesday, March 4, at 10:00 am](#). The hearing will take place in 2358-C Rayburn House Office Building and will also be webcast. Dr. Collins will be joined by Institute directors Diana Bianchi, MD (NICHD), Anthony Fauci, MD (NIAID), Gary Gibbons, MD (NHLBI), Ned Sharpless, MD (NCI), and Nora Volkow, MD (NIDA).

#### **Congress Seeks Supplemental Funding for Coronavirus**

Lawmakers in both the House and Senate announced plans to draft an emergency supplemental spending bill expected to exceed the [\\$2.5 billion request](#) submitted by the White House on February 24 to battle Coronavirus Disease 2019 (COVID-19). The White House request specifies \$1 billion for vaccine development for NIH and proposed to reallocate funds from other existing sources such as the Ebola virus response. Several agency officials, including NIAID Director Anthony Fauci, MD, will [testify before the Senate HELP Committee](#) on Tuesday, March 3 regarding COVID-19. The hearing will take place at 10:00am in 430 Dirksen Senate Office Building.

## **NIAID and CDC Directors Author *NEJM* Commentary on Coronavirus**

As described in an [NIH press release](#), NIAID Director Anthony Fauci, MD, co-authored a February 28 *New England Journal of Medicine* commentary on the current COVID-19 outbreak. The authors review the ongoing outbreak, describe the current understanding of COVID-19 transmission, and discuss how the disease may continue to spread, including precautionary measures to take to limit continued transmission.

## **Director's Blog: Interview with Rare Disease Warrior for Rare Disease Day**

To raise awareness for Rare Disease Day on February 28, NIH Director Francis Collins, MD, PhD, interviewed clinician and rare disease patient David Fajgenbaum, MD, for the [Director's Blog](#). Dr. Fajgenbaum is an NIH-funded immunologist who was diagnosed with a rare disease called idiopathic multicentric Castleman disease (iMCD) while in medical school. The two discussed the importance of research and advocacy to make progress against the more than 7,000 rare diseases that impact 1 in 10 Americans.

## **NIH News Release: Hearing Health Care is a Global Priority**

Debara Tucci, MD, director of the National Institute for Deafness and Other Communication Disorders (NIDCD) [published a statement](#) in advance of World Hearing Day on March 3. 466 million individuals across the world suffer from disabling hearing loss, and unaddressed hearing loss costs an estimated \$750 billion annually worldwide. Dr. Tucci highlights NIDCD's efforts to support research and various domestic and global public health initiatives to address hearing loss.

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

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### **NEW Congressional Briefing: The Affordable Care Act at 10: Celebrating a Decade of Progress for Patients – March 5**

Join the Partnership to Protect Coverage to learn about how hard it was to get health insurance before the Affordable Care Act, how access to care and health outcomes have steadily improved since its passage in 2010, and what comes next in 2020 and beyond. Two briefings will take place on Thursday, March 5 – the first taking place at 12:00pm in [106 Dirksen Senate Office Building](#), followed by the second at 2:00pm in [HVC-201AB in the U.S. Capitol Visitor Center](#). [Please RSVP](#) by March 4.

### **Maternal Health Briefing - March 5, 2020**

Please join the American Heart Association and WomenHeart for a congressional briefing *Heart Health and Pregnancy* on Thursday, March 5, 2020 from 1:00 - 2:00 pm in Rayburn Gold Room 2168. Learn about the impact of heart disease on maternal health and how research and practice are addressing disparities in outcomes for women of color. Please see [attached flyer](#) for details and RSVP to [monica.mccall@heart.org](mailto:monica.mccall@heart.org).

### **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 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**

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### **Request for Public Comment on Characteristics of Data Repositories – March 6**

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 March 6 deadline.

### **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.

### **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 March 16.

## **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**

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### **NEW 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](mailto: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](mailto:chwagner@aamc.org) or Tannaz Rasouli at [trasouli@aamc.org](mailto:trasouli@aamc.org).*