



## THE AD HOC GROUP FOR MEDICAL RESEARCH

### Ad Hoc Group Weekly Round Up

February 24, 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:

#### **Alzheimer's Association @alzassociation February 6**

Thank you, [@NBCThisIsUs](#), for exploring the tough conversations families have when a loved one is experiencing memory loss. It's important to have these conversations early to plan for the future. Hear real-life stories at [alz.org/stories](#). [#ThisIsUs](#) [#ENDALZ](#)

#### **HHS Secretary to Testify on FY 2021 Budget, Coronavirus**

HHS Secretary Alex Azar is scheduled to testify before four Congressional committees during the week of February 24 regarding the president's FY 2021 budget proposal, as well as the ongoing coronavirus outbreak. Secretary Azar will testify:

- February 25: [Senate Appropriations Labor-HHS Subcommittee](#), 10:30 am
- February 26: [House Appropriations Labor-HHS Subcommittee](#), 9:30 am
- February 26: [House Energy and Commerce Health Subcommittee](#), 1:30 pm
- February 27: [House Ways and Means Committee](#), 10:00 am

#### **Fox: Blunt, Cole Author Opinion Piece on Return on Federal Health Investments**

Senator Roy Blunt (R-Mo.) and Representative Tom Cole (R-Okla.) co-authored a February 18 [opinion in Fox News](#) drawing a connection between the recently reported increase in Americans' life expectancy, and the federal investments in medical research and public health programs. They write, "As the chairman and ranking member of the congressional subcommittees responsible for funding federal health efforts, we were pleased to see proof that smart investments in medical research, care, and prevention can help save lives."

#### **HHS Seeks Nominations for NIH Fetal Tissue Research Ethics Advisory Board**

On February 20, HHS published a long-anticipated [call for nominations](#) to the agency's new Human Fetal Tissue Ethics Advisory Board, one component of a set of new fetal tissue research policies the administration announced in June 2019. Nominations are due

by March 20. As outlined in the Public Health Service Act, the board will be composed of 15 nonfederal employees to include: no fewer than one attorney; no fewer than one ethicist; no fewer than one practicing physician; and no fewer than one theologian. No fewer than one-third, and no more than one-half, of the appointed members will be scientists with substantial accomplishments in biomedical or behavioral research.

### **House Members Investigate Racial Profiling of Chinese Scientists**

On February 20, House Oversight Civil Rights and Civil Liberties Subcommittee Chair Jamie Raskin (D-Md.) and Rep. Judy Chu (D-Calif.) sent a letter to [National Institutes of Health](#) Director Francis Collins, MD, PhD, indicating they are investigating potential racial profiling in ongoing agency investigations of foreign government influence in medical research. The members requested that NIH respond by March 5.

### **NCI Director Shares Perspective on FY 2020 Budget**

Newly re-instated NCI Director Ned Sharpless, MD, authored a Perspective in the [February 2020 AACI Commentary](#). Dr. Sharpless gave an overview of the National Cancer Institute's (NCI) FY 2020 budget, outlined his rationale for defining the present as a "golden age" of cancer research, and shared insight into NCI's efforts to plan for budget uncertainty while upholding previous funding commitments.

### **NIH Podcast on Diversity and Supplement Programs**

The latest [NIH All About Grants podcast](#), released February 19, includes a conversation with National Institute of General Medical Sciences Director Jon Lorsch, PhD. Dr. Lorsch discusses NIH's interest in diversifying the research workforce, including information on who is eligible for specific funding opportunities, and how diversity supplements can help career development.

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

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### **NEW Congressional Briefing on Coronavirus – February 26**

Please join the Congressional Biomedical Research caucus for a briefing titled, "What We Know About the Coronavirus," presented by University of North Carolina epidemiologist Ralph Baric, PhD. The briefing will be held on Wednesday, February 26, from 2:30-3:30pm in 121 Canon House Office Building. RSVP to [cls@coalitionforlifesciences.org](mailto:cls@coalitionforlifesciences.org) and see the [briefing flyer](#) for additional information.

### **Celebrating Rare Disease Research Advocates – February 26**

Please join Research!America and partners for a reception honoring advocates for the critical role they play in faster progress against rare disease. The program will feature a brief interactive conversation about rare disease caregiving, research, and advocacy. The event will take place on Wednesday, February 26, from 5:30-7:30pm at The W Hotel in Washington D.C. [Please visit the event website](#) for more details and to register.

### **Reeve Summit 2020 – February 26-28**

The Christopher & Dana Reeve Foundation is hosting its first national conference in Washington, DC, February 26-28. Reeve Summit 2020 will bring together those who have had an extraordinary impact on the lives of people with paralysis and related disabilities,

including 300 community members, health professionals and caregivers, and will include powerful keynotes, educational sessions, and opportunities to connect with those who are changing the culture and reality of spinal cord injury. Please contact Kim Beer at [kbeer@christopherreeve.org](mailto:kbeer@christopherreeve.org) with any questions about the conference. Registration and more information can be found [on the event website](#).

### **Workshop on Emerging Bioethical Issues in Biomedical Research – February 26**

On February 26, NIH will be sponsoring a workshop conducted by the National Academy of Sciences, Engineering, and Medicine to examine emerging bioethical issues related to biomedical research. The workshop will begin at 8:30am and take place at 500 Fifth St. NW, or can be viewed via webcast. Please visit [the workshop website](#) for additional details and to register.

### **Congressional Briefing on Glaucoma Research and Practice – February 26**

Please join the Alliance for Eye and Vision Research as they co-host a congressional briefing titled, “The Impact of Federal Funding on Glaucoma Research and Clinical Practice.” The briefing will take place on Wednesday, February 26, from 12:00-1:15pm in 2045 Rayburn House Office Building. Please see [attached flyer](#) for additional details, and RSVP to Dina Beaumont at 202-407-8325 or [dinabeau@aol.com](mailto:dinabeau@aol.com).

### **NEW 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**

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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### **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).*