



## THE AD HOC GROUP FOR MEDICAL RESEARCH

### Ad Hoc Group Weekly Round Up

February 18, 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:

#### **All of Us Emory [@AllofUsEmory](#) February 6**

"Rural Americans have long faced significant health challenges — we're nearly 40% more likely to suffer from coronary heart disease..." Read this [@ruralhealth](#) article on [health in rural communities](#) + the [@AllofUsResearch](#) Program [#JoinAllofUs](#)

#### **President's FY 2021 Budget Proposes \$38.7B for NIH; Ad Hoc Group Recommends \$44.7B for NIH**

As reported February 10, the president's [FY 2021 budget request](#) proposes a \$3 billion, or 7.2% cut, to NIH. HHS also released its [Budget in Brief](#), and NIH released its FY 2021 [Congressional Justification](#). The Ad Hoc Group for Medical Research [released a press statement](#) urging Congress to reject the proposal which would "would devastate the agency's ability to pursue promising new science to improve and save lives."

Simultaneously, the Ad Hoc Group released its [FY 2021 recommendation of \\$44.7 billion for NIH](#), a \$3 billion increase over the comparable FY 2020 level. This recommendation is supported by more than 330 organizations and institutions across the medical research advocacy community.

#### **Get to Know the NIH Institutes: NIBIB**

The National Institute of Biomedical Imaging and Bioengineering (NIBIB) is one of NIH's youngest institutes and collaborates across all other Institutes and Centers through sharing engineering expertise. Learn more about NIBIB's development of [cutting edge](#) technologies, [Concept to Clinic](#) entrepreneurial opportunities, and the [SPARC](#) Common

Fund program. You can sign up to receive weekly updates from NIBIB at the bottom of the [institute home page](#).

## **NIH Director Interviewed on Yahoo Finance Influencers**

[NIH Director Francis Collins, MD, PhD, was interviewed](#) by Andy Serwer on Yahoo Finance Influencers on February 6. The interview covered a discussion of the novel coronavirus, seasonal flu, and other health topics.

## **UMR Releases 2020 Report on NIH's Economic Impact**

On February 13, United for Medical Research released its [2020 report "NIH's Role in Sustaining the U.S. Economy"](#). The report shows that research funded by the NIH saves lives, improves health, and offers hope to people the world-over affected by disease. It also supports nearly 476,000 jobs and more than \$81 billion in economic activity across the United States, making the NIH a research and economic powerhouse.

## ***Washington Post*: Why We Can't Cure Cancer with a Moonshot**

In a February 11 [Washington Post opinion piece](#), 2019 Nobel Laureate William Kaelin, Jr., MD, describes why basic research is so important to cancer medicine. He explains, "Science generates new knowledge ('learning the rules'), whereas engineering applies that knowledge ('using the rules')." An unbalanced focus on deliverables and products - the moonshot metaphor - can be a disservice. Dr. Kaelin is a professor of medicine at the Dana-Farber Cancer Institute, Brigham and Women's Hospital and Harvard Medical School and a Howard Hughes Medical Institute investigator.

## **Science: Dance Your PhD Winners Announced**

The winners of the [2020 Science magazine "Dance Your PhD" contest](#) were announced on February 14. According to the description, "The contest challenges scientists around the world to explain their research through the most jargon-free medium available: interpretive dance." This year's grand prize winner danced her research studying social interactions in larval zebrafish.

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

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### **NEW 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).

### **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.

## **NEW NNIH Seeks Community 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.

## **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.

## **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).*