

THE AD HOC GROUP FOR MEDICAL RESEARCH

Ad Hoc Group Weekly Round Up

January 6, 2020

Happy New Year!

Each week, the Ad Hoc Group Weekly Round Up will feature hashtags and/or tweets (follow us at <u>@fundNIH</u>) 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:

Research!America @ResearchAmerica

Federal government spending [in health-related research] grew by \$2.2 billion or 5.5% from 2017 to 2018, and by \$9.1 billion or 26.9% from 2013 to 2018. See the breakdown of federal investment in Medical and Health R&D by sector and more in our newest report. <u>http://ow.ly/RhD150xDoR8</u>

President Signs FY 2020 Spending Bills Into Law

President December 20 signed into law the Further Consolidated Appropriations Act, 2020 (H.R. 1865), funding federal agencies for the remainder of FY 2020 through eight of the annual spending bills, including the Labor-HHS spending bill with joint explanatory statement. The final FY 2020 Labor-HHS spending bill provides a total of \$41.7 billion for NIH, including the full \$492 million provided in FY 2020 through the Innovation Account established in the 21st Century Cures Act for specific initiatives. This total funding level represents a \$2.6 billion or 6.7% increase over the comparable FY 2019 funding level — the fifth consecutive increase of \$2 billion or more since FY 2016 — and falls between the House-passed \$41.1 billion and the Senate-proposed \$42.1 billion for the agency in FY 2020.

The Ad Hoc Group for Medical Research issued a Dec. 17 <u>press statement</u> commending lawmakers for their efforts "to expand NIH's capacity to support foundational and life-saving research."

President's FY 2021 Budget Expected February 10

<u>CQ January 6 reports</u> that the White House plans to release a full budget request on February 10 (subscription required). The release includes a reminder that under the Bipartisan Budget Act of 2019, "fiscal 2021 discretionary appropriations will be capped at just \$5 billion above the current fiscal year, or \$1.375 trillion," to be evenly divided between defense and nondefense funding.

Celebrating 2019 Biomedical Breakthroughs

NIH Director Francis Collins, MD, PhD, posted a <u>January 2 blog post</u> reviewing top biomedical research breakthroughs of 2019, listed as runners-up in the <u>Science magazine</u> 2019 Breakthrough of the Year story on the first imaging of a black hole. Notable medical research-related stories include: microbes combating malnourishment; a drug treats most

cases of cystic fibrosis; therapeutic hope for Ebola patients; and a report on the public health breakdown through a resurgence of measles.

Discover Magazine: NIH Director Discusses Human Gene Editing

NIH Director Francis Collins, MD, PhD, authored <u>a December 29 op-ed in *Discover* magazine</u> reviewing advances in CRISPR in 2019, as well as NIH's stance on human gene editing. Dr. Collins shared that while NIH has a "strong stance against heritable gene editing," the agency made it a high priority in 2019 to fund research using nonheritable gene editing to address rare diseases. Dr. Collins concluded that, "A moratorium of at least five years on heritable human gene editing would provide us time to engage in proactive, rather than reactive, discussions about the future of such technology."

HHS to Solicit Nominations for Human Fetal Tissue Research Ethics Advisory Board

The NIH December 23 issued a guide notice indicating that in early 2020 the US Department of Health and Human Services (HHS) intends to request nominations for members of a Human Fetal Tissue Research Ethics Advisory Board. Originally announced by HHS in June 2019 and further described with new NIH human fetal tissue research policies in July 2019, the Ethics Board will advise the HHS Secretary on whether NIH should fund specific proposed research using human fetal tissue. The notice indicates that the Ethics Board will likely convene annually, beginning this year.

Open Mike: Predicting Translational Research Progress

In a <u>December 17 blog post</u>, NIH Deputy Director for Extramural Research Mike Lauer, MD, summarized a recent *PLOS Biology* paper describing "a machine-learning strategy that taps into the trajectory of science by tracking knowledge flow from bench to bedside." The results, authored by staff from the NIH Office of Portfolio Analysis, indicate that predictions on whether a basic research finding will be included in a future clinical trial or guideline can be predicted within two years of the initial publication.

Open Mike: Data Are Available on NIH Funding Plans

On December 23, NIH Deputy Director for Extramural Research Mike Lauer, MD, continued his <u>Open Mike blog discussion on how NIH makes its funding decisions</u>. The NIH intends to publish more data on its funding strategies as laid out in its <u>Strategic Plan</u> for Fiscal Years 2016-2020. Dr. Lauer explained that while peer review scores are an essential part of the decision, NIH Institutes and Centers also factor in the entire research portfolio, unmet scientific needs, and recent unexpected breakthroughs, as well as training, workforce, and infrastructure needs. Dr. Lauer also presented FY 2018 data on R01-equivalent applications and R56-Bridge awards.

Nature: Keep US Research Open Amid Threat from China, Says JASON Group

A <u>December 11 article in *Nature*</u> explained that the science advisory group, JASON, acknowledged that the threat of improper influence on American science from China is real and growing, but also warned that the US government should keep the research enterprise open so the country can still attract top international talent. "The benefits of openness in research and of the inclusion of talented foreign researchers dictate against measures that would wall off particular areas of fundamental research," <u>said the group's report to the NSF</u>, which included analysis of NIH data on foreign government influence.

NIH Draft Policy for Data Sharing and Management Public Comment – January 10

The NIH November 6 released for public comment in the <u>Federal Register</u> a Draft NIH Policy for Data Management and Sharing along with supplement draft guidance. According to <u>a blog post authored by NIH Associate Director of Science Policy</u>, Carrie Wolinetz, PhD, "The draft policy furthers NIH longstanding commitment to making available the results and products of the research we fund and conduct." NIH has established a <u>web-portal where the public can provide their feedback</u>. Responses must be submitted no later than January 10, 2020.

NIH NSABB Meeting – January 23-24

The National Science Advisory Board for Biosecurity (NSABB), a federal advisory committee, will meet January 23-24 to discuss sharing information about research involving enhanced potential pandemic pathogens and other items. The meeting in Bethesda, MD, is open to the public and will be webcast. A link to pre-register and view draft agendas is on <u>the meeting website</u>.

OSTP Extends Deadline for Comments on the American Research Environment – January 28

The White House Office of Science and Technology Policy (OSTP) <u>recently extended</u> the deadline for a <u>request for information (RFI) on the American Research Environment</u> originally published in the Federal Register. On behalf of the Joint Committee on the Research Environment (JCORE), OSTP seeks comments on "actions that Federal agencies can take, working in partnership with private industry, academic institutions, and non-profit/philanthropic organizations, to maximize the quality and effectiveness of the American research environment." Comments are due by January 28 via email to the National Science and Technology Council Executive Director, Chloe Kontos at JCORE@ostp.eop.gov.

NIH to Host Workshop on NHP Models and Charting the Path Forward – February 18-19

The <u>NIH plans to convene a workshop</u> on the "unique challenges and important generalizable lessons in terms of science, welfare, and ethics" of research on non-human primates (NHPs) on February 18-19. The workshop will "identify emergent challenges facing the conduct, reproducibility, and translation of rigorous research when working with NHP models and discuss strategies for addressing these challenges, including building on or augmenting current best practices." Logistical details will be forthcoming, and the workshop will be available by videocast.

NLM Requesting Information on ClinicalTrials.gov Modernization – March 14

The NIH's <u>National Library of Medicine (NLM)</u> is requesting comments on its multi-year plans to modernize <u>ClinicalTrials.gov</u>, 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.

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. <u>Visit the meeting website</u> to learn more about the program and to register; early bird registration rates apply through December 31.

Job Postings

March of Dimes Seeks Manager, Advocacy Mission Marketing

The March of Dimes seeks a Manager to lead the execution of advocacy campaigns to ensure March of Dimes issues are top of mind for policymakers at the state and federal level. Job responsibilities include managing the execution of March of Dimes grassroots advocacy efforts, communicating with supporters on the Advocacy Network, growing and acquiring new advocates to join our Advocacy Network email and mobile list, and more. Please visit the job posting website for more information and instructions on how to apply.

The Myositis Association Seeks Director, Communications & Research

The Myositis Association is seeking a new Director of Communications & Research's to raise the visibility of TMA and myositis diseases among key audiences and to position TMA as the "go to" organization/source for information, research and clinical trial updates, and support resources and services for the myositis patient, care partner, and medical community. <u>Please visit the job posting</u> to learn more and to apply.

APS Seeks Science Policy Analyst

The American Physiological Society seeks a Science Policy Analyst to develop and implement advocacy strategies on issues related to animal research, research funding, and other policy issues. Please review the <u>position description</u> carefully. You may apply by visiting <u>https://www.faseb.org/About-FASEB/Careers.aspx</u> or by emailing a cover letter, resume, and policy-oriented writing sample to <u>resumes@faseb.org</u>.

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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.

HIVMA Clinical Fellowship Program – Deadline Jan. 7

The HIV Medicine Association awards grants to support one-year of HIV clinical training to up to two fellows per year. Grants are made to the institution to support the fellow's stipend, to offset administrative costs, and to provide for additional educational opportunities. One of the program's goals is to increase the diversity of the HIV clinical workforce particularly from populations and communities that have been disproportionately impacted by HIV. Physicians who are underrepresented in medicine or interested in working in the Southeastern US are strongly encouraged to apply. The application deadline is January 7, 2020. For more information, please contact <u>Asha Farrah</u> or <u>visit the fellowship website</u>.

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 <u>chwagner@aamc.org</u> or Tannaz Rasouli at <u>trasouli@aamc.org</u>.