

Ad Hoc Group Weekly Round Up – January 28, 2019

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:

[United for Medical Research @UMR4NIH](#)

Why is it essential to continue to invest strongly in medical research? Because it's a long, difficult process, but it does yield [#AmazingThings](#) [#keepNIHstrong](#): https://www.statnews.com/2019/01/16/stem-cell-therapies-macular-degeneration/?utm_content=buffer51a3d&utm_medium=social&utm_source=twitter&utm_campaign=twitter_organic

1. President Signs Continuing Resolution through Feb. 15

President Trump Jan 25. signed into law a 3-week long continuing resolution for the nine unfunded cabinets and agencies, including health and science agencies such as FDA, IHS, and NSF. A [Jan. 19 news article](#) in *Science* reviewed the effects of the government shutdown on science agencies that remained funded, such as the NIH. In the article, staff writers note that the agency funding the public notice resource the *Federal Register* was impacted by the shutdown.

2. NDD United Sign-On Opportunity

Sequestration will again become a part of the appropriations discussion as the temporary and partial relief of the Bipartisan Budget Act of 2018 expires at the end of FY 2019. In the 116th Congress, threats to nondefense discretionary programs face a steep, \$55 billion funding cliff that would reverse many of the funding gains made in the last few years.

In an effort to protect NDD programs from further cuts and to end sequestration, NDD United is circulating a sign-on letter urging lawmakers to negotiate a new budget agreement providing relief from the discretionary spending caps in FYs 2020 and 2021. The Ad Hoc Group has signed on to the letter, and we encourage individual organizations to do so as well. You can review the letter [here](#) and [complete the sign on form here](#). Deadline to sign on is Jan. 31.

3. All of Us Year-End Update and 2019 Prospectus

NIH's *All of Us* Research Program Dec. 20 posted a video to share a [year-end summary](#) of the program. Highlights from *All of Us* Director Eric Dishman include 150,000 program participants from all 50 states, including 75% of participants from underrepresented minorities. The program Jan. 10 [posted a forward-looking video](#) with *All of Us* plans for 2019, including pilot programs to return research results, and a new tool to view electronic health records.

4. Op-Ed: Invest in Innovation to Decrease Health Spending

FasterCures Executive Director Tanisha Carino, PhD, in a Jan. 24 [Health Affairs blog post](#) makes a case for investing in U.S. biomedical research and development. She notes, "In the FY2019 budget, the [NIH] received a \$2 billion increase ... this boost is an important step. But

...it still leaves NIH's purchasing power below its 2003 level, which translates to a \$5 billion funding gap." She continues that the 2016 passage of the 21st Century Cures Act has also created a foundation that policymakers can improve upon by increasing safety, incentivizing innovation broadly, and increasing the capacity of patient organizations.

5. *Open Mike* Blog: Curling Up with a New NIH Data Book

NIH Deputy Director for Extramural Research Michael Lauer, MD, Jan. 24 in his *Open Mike Blog* announced a new edition of the [NIH Data Book](#) updated with data for 2018. Dr. Lauer notes, "For over a decade, the NIH Data Book has served as a helpful resource for describing funding trends on grants and contract awards, success rates, small business programs, peer review, as well as the scientific workforce." The book's format has been upgraded to provide "interactive visualizations and more configuration options to make it easier for you to find the information you need." A legacy version in the book's previous format will be available until April to help compare and navigate the changes.

6. *Open Mike* Blog: Year in Reflection 2018

NIH Deputy Director for Extramural Research Michael Lauer, MD, Jan. 28 authored an additional [blog post](#), reflecting on the blog's outreach in 2018. Dr. Lauer used the analogy of the uncertainty in decision making, and incorporating NIH, sharing that "At NIH, we seek to develop and implement policies and processes that lead to improved rigor, stewardship, transparency, and integrity" which includes elements of decisions about grant funding, and the probability of success of those funded projects. Dr. Lauer also reflects on the decisions his team makes to post topics on the *Open Mike* blog that they hope will be beneficial to readers. He lists the top 10 most read blogs of 2018, and encourages readers to share additional topics of interest for 2019.

7. *Extramural Nexus*: A New Protection of Human Subjects Website

The NIH Jan. 25 announced the launch of a new [Protection of Human Subjects website](#). The announcement notes, "On the new Protection of Human Subjects site, you can find useful information about proposing and conducting NIH extramural research involving human subjects, including policies, regulations, training, resources, and updated information on the revised human subject regulation (Common Rule)."

Upcoming Hill Briefings and Other Events

8. Congressional Briefing on Neuroscience Research – Jan. 29

The federal government – mostly but not exclusively through the NIH – has played a critical role in supporting the foundational knowledge that makes translational and clinical research possible. Congress has increased funding for the NIH for the past four consecutive years. Of the \$39.1 billion provided in FY2019, NIH estimates that it will be devoting more than \$7 billion to neuroscience research. In addition, scientists are actively working to develop new tools as part of the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. This briefing, "Bench to Bedside: Building from Neuroscience Research Discoveries," will build on the successes within the neuroscience research community over the past few years and discuss the need to leverage increased federal funding with private investment to ensure that novel therapies are available to the people who most need them. The briefing will take place on

Tuesday, Jan. 29, from 12-1:30pm in 2045 Rayburn House Office Building. View the official flyer for the event [here](#), and please RSVP to Tamara Criss at crdfellow3@dc-crd.org.

9. NAM Webinar on Action Collaborative Countering Opioid Epidemic – Feb. 13

The National Academy of Medicine (NAM) is hosting a [free webinar](#): “An Introduction to the Action Collaborative on Countering the US Opioid Epidemic” on February 13 from 4:00-5:00pm. The webinar will describe the Collaborative's work towards better coordination, information-sharing, and evidence-based practice of the many efforts being taken to fight the opioid epidemic. The overview will be followed by updates from the Collaborative's four working groups and a Q&A.

10. AdvaMedDx and ACS CAN Congressional Briefing – Feb. 14

AdvaMedDx and the American Cancer Society Cancer Action Network (ACS CAN) invite you to a congressional briefing titled “Accelerating Global Elimination of Cervical Cancer: A Call to Action.” The briefing will cover how, with U.S. investment and leadership, we can accelerate the elimination of cervical cancer death globally, saving hundreds of thousands of lives. The briefing will take place from 12-1:30pm on Feb. 14 in 2017 Rayburn House Office Building. Please [RSVP by Feb. 12](#) and see attached for additional information.

11. AAMC/FASEB Webinar on NAS’s Next Generation of Researchers Report – Feb. 19

The Association of American Medical Colleges (AAMC) and the Federation of American Societies for Experimental Biology (FASEB) are hosting the fourth webinar in their 2018/2019 National Academies reports [webinar series](#). Program Officer Lida Beninson, PhD, of the National Academies, will unpack the key findings of the report “[The Next Generation of Biomedical and behavioral Sciences Researchers Breaking Through](#).” The webinar is being held on Feb. 19, 1:00-2:00 PM ET and free [registration](#) is required.

12. NCATS Hosting its Rare Disease Day – Feb. 28

The NIH's National Center for Advancing Translational Sciences (NCATS) with the NIH Clinical Center is hosting [Rare Disease Day](#) on Feb. 28 on the NIH campus in Bethesda, MD. The annual event is intended to raise awareness about these diseases, the people they affect, and new research opportunities through panel discussions, posters, artwork, tours, and networking opportunities. Speakers include NIH Director Francis Collins, MD, PhD; NCATS Director Christopher Austin, MD; and NIH Clinical Center CEO James Gilman, MD. Admission is complimentary and open to the public. On February 22, NIH will host a Twitter chat on rare diseases from 1-2 PM ET featuring Drs. Collins, Austin, and Gilman as well as representatives from the rare diseases advocacy community.

Job Postings

Science Policy Branch at NIDA Seeks Two Policy Analysts

NIDA's Science Policy Branch is responsible for policy analysis, synthesizing the latest NIDA-funded scientific findings into briefing materials for leadership, responding to inquiries from a wide variety of stakeholders, strategic planning, and performance reporting. Read more [here](#) about the Science Policy Branch.

NIDA seeks motivated candidates with expertise in addiction science and/or addiction policy. There are two different sets of NIH-wide postings through which NIDA is seeking candidates: a Social and Behavioral Health Scientist Administrator ([public](#) and [internal](#) applications), and a Health Scientist Administrator ([public](#) and [internal](#) applications). All interested parties should apply by January 31.

NIA Seeks Analyst to Join the Office of Legislation, Policy, and International Activities

The Office of Legislation, Policy, and International Activities (OLPIA) at the National Institute on Aging (NIA) is planning to recruit a Health Science Policy Analyst to facilitate critical communications with a wide range of internal and external NIA audiences and stakeholders (including Congress, non-governmental organizations, disease advocates, and more), provide external relations support to NIA leadership, and augment office capabilities across a wide range of aging research-related activities. OLPIA, a small but growing office housed in the NIA Office of the Director, offers a fast-paced, high-visibility, collegial work environment, and the health science policy analyst position will be essential to take advantage of critical, new opportunities to extend the NIA's U.S. and global network and impact. View the [posting](#) for details and to apply.

ALS Seeks Associate Director, Grassroots Advocacy

Bring your passion and leadership to join the fight against ALS! The Associate Director, Grassroots Advocacy will report to the Vice President, Public Policy and work as part of a team with the Associate Director for Government Affairs and the Public Policy Manager. The successful candidate will design and direct nonpartisan grassroots activities, including managing an annual Fly-In and the National ALS Advocacy Conference and working with ALS chapters and volunteer leaders. While federal level advocacy is the main focus, the candidate will also develop a new program to support chapters on state level advocacy. [Apply here](#).

PCORI Seeks Associate Director, Public Policy

The Patient-Centered Outcomes Research Institute seeks an Association Director, Public Policy. Position responsibilities include: supporting the Director for Public Policy and Government Relations, Chief Engagement and Dissemination Officer, and the PCORI Board of Governors and executives in representing PCORI with Congress, including members, committee staff and legislative staff; support the development and implementation of PCORI's strategic plan related to reauthorization; and more. Please visit the [job posting](#) to apply.

FASEB Seeks Senior Science Policy Analyst

The Federation of American Societies for Experimental Biology seeks a Senior Science Policy Analyst. Primary functions of the role include analyzing science policy issues and independently managing committees, projects, reports, and seminars/workshops pertaining to the training and development of the biological and biomedical workforce and other topics of concern to the sustainability of the research enterprise. Please visit FASEB's [employment opportunities](#) site for [additional information](#) and a [link to apply](#).

ASHG Seeks Two Policy and Advocacy Positions

The American Society of Human Genetics (ASHG), the primary professional membership organization for human genetics specialists worldwide, seeks a Policy & Advocacy Assistant. This person will report to the Senior Director, Policy and Advocacy, and will help fulfill the Society's advocacy role by helping to develop advocacy resources for members; supporting the development of policy statements; and coordinating policy and advocacy-related events and other administrative duties. Please visit FASEB's [employment opportunities](#) site for [additional information](#) and a [link to apply](#).

ASHG also seeks a Policy & Advocacy Manager. This person will report to the Senior Director, Policy and Advocacy, and will help fulfill the Society's policy and advocacy functions by tracking, analyzing and drafting material on policy issues; staffing volunteer bodies to develop policy material and advocacy programming; helping to build and then manage advocacy activity of Society's leadership and membership; and strengthening relations with Congress. Please visit FASEB's [employment opportunities](#) site to learn more and to apply.

National MS Society Seeks Manager, Government Relations

The National Multiple Sclerosis Society mobilizes people and resources to drive research for a cure and to address the challenges of everyone affected by MS. The Manager, Government Relations, will provide advocacy and policy support across all of the Society's activism. The position will directly lobby Congress, as well as implement advocacy and lobbying strategies and tactics at the federal and state levels. The position will be responsible for public policy and legislative research and analysis to help determine, assess and manage the Society's federal, state and local policy priorities. Additionally, the position will engage with advocacy staff and volunteers across the country. For more information and to apply, click [here](#).

University of Florida Seeks Assistant Director of Federal Relations

The University of Florida Seeks an Assistant Director of Federal Relations for the Washington, D.C. office. Essential job functions include: manage and execute the government relations program for a portfolio of the University's federal interests; anticipate, monitor and analyze federal policy, funding developments, legislation and regulations, and provide regular reporting to internal stakeholders; build and maintain relationships with key legislative branch and executive branch officials, their staff members, and higher education and other policy advocates and associations; and more. More details and application instructions are available on the [job posting site](#).

American Heart Association Seeks Regulatory Affairs Manager

Under the direction of the Vice President of Federal Advocacy, the [Regulatory Affairs Manager](#) would be responsible for monitoring, analyzing, and drafting responses to a prescribed set of federal regulatory and reimbursement-related issues that impact the association's public policy agenda. The primary focus of the AHA's regulatory work is with the Department of Health and Human Services and its key agencies. Major topics would include rules that impact ACA markets and patient protections, Medicare coverage determinations and Medicare payment rules, and FDA initiatives focused on drug/device development and safety.

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.