

Ad Hoc Group Weekly Round Up – July 29, 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:

[Academy for Radiology & Biomedical Imaging Res. @AcadRad](#)

"This budget deal is so important, and it's all about the money." - [@LindseyGrahamSC](#) speaking on the importance of increasing the [@NIH](#) budget and the current deal to [#RaiseTheCaps](#). [@ACTforNIH](#)

1. House Passes Deal to Raise Budget Caps, Senate to Consider Week of July 29

The House July 25 approved, [284-149](#), a budget agreement ([H.R. 3877](#)) that would suspend the debt ceiling through July 31, 2021, and revise discretionary spending caps for two years. If enacted, the revised spending cap would avert \$55 billion in cuts to non-defense discretionary (NDD) spending that would occur under the statutory Budget Control Act cap for FY 2020; by contrast, the revised cap would represent a \$24.5 billion (4.1%) increase over the comparable funding level in the FY 2019 spending bills. This cap falls below the \$631 billion cap "deemed" by the House to draft its FY 2020 spending bills, including the HHS spending bill ([H.R. 2740](#)), which included a \$2 billion increase for NIH.

The Ad Hoc Group Executive Director sent [July 24](#) and [July 26](#) letters urging all House and Senate offices, respectively, to support the budget agreement. The letter notes, "To keep pace with scientific opportunity, we must ensure an investment in [the NIH] in FY 2020, that, at minimum, matches the funding level approved by the House, and your support for H.R. 3877 would mark a necessary first step in advancing this life-saving research and other discretionary spending priorities in FY 2020 and beyond." The Senate is expected to vote on the agreement the week of July 29, and Senate appropriators could begin considering spending bills in September.

2. Sen. Alexander Urges Support for Two-Year Budget Caps Deal

Sen. Lamar Alexander (R-Tenn.) July 25 made remarks on the Senate floor and was quoted in [The Chattanooga](#) urging Senators to support the two-year budget caps deal negotiated by Congressional leaders and the Trump administration. Sen. Alexander shared examples of groundbreaking research conducted with NIH funding as reported by NIH Director Francis Collins, MD, PhD, such as the artificial pancreas and advances in sickle cell disease. Sen. Alexander added, "With this new two year budget agreement, Congress could increase funding for NIH for a 6th consecutive year to continue its life saving research."

3. NIH Shares Updates on Basic Research Involving Human Subjects

The NIH July 24 issued a [notice](#) to "extend interim policy flexibilities regarding registration and results reporting for a subset of NIH-funded research whose primary purpose is basic experimental studies with humans (BESH)." The extension lasts until September 24, 2021. Director of the NIH Office of Behavioral and Social Sciences Research William Riley, PhD, NIH Deputy Director for Extramural Research Mike Lauer, MD, and Associate Director for Science Policy Carrie Wolinetz, PhD, co-authored a [blog post](#) to expand on the update, noting that responses to an earlier [RFI](#) indicate that some researchers have found it challenging to register

and report results for BESH on ClinicalTrials.gov. The authors also convey NIH's goal of "understand[ing] more fully the challenges of disseminating information about BESH and explore solutions that are meaningful and useful to other researchers and members of the public."

4. NIH Announces Network to Improve Substance Use Treatment in Criminal Justice Setting

The NIH July 24 [announced](#) new funding to "support research on quality addiction treatment for opioid use disorder in criminal justice settings" as a part of the HEAL Initiative under the National Institute of Drug Abuse (NIDA). The Justice Community Opioid Innovation Network (JCOIN) will support \$155 million of research at 12 institutions nationwide. NIDA Director Nora Volkow, MD added, "It is vitally important to provide evidence-based approaches for people leaving criminal justice facilities in order to prevent relapse and opioid overdose which often occurs as they transition back into their communities."

5. Changes to NIH Requirements Regarding Proposed Human Fetal Tissue Research

The NIH July 26 issued a [guide notice](#) to inform the research community of immediate changes to the documentation requirements for extramural funding including human fetal tissue research, such as additional information in the Approach section, additional budget details on the cost of acquisition of tissue, and review by a federal ethics advisory board. This follows HHS's June 5th [announcement](#) of policy and regulatory changes regarding research with fetal tissue from an elective abortion.

6. STAT: NIA Director on the State of Alzheimer's

National Institute of Aging Director Richard Hodes, MD, participated in a [Q&A](#) with *STAT* at the recent Alzheimer's Association National Conference, published July 26. The conversation covered several topics including: the current state of drug discovery and molecular targets for new Alzheimer's drugs; research funding; and challenges with clinical trials for Alzheimer's disease.

7. House Passes Sexual Harassment Legislation

The House of Representatives July 23 passed by voice vote the Combating Sexual Harassment in Science Act of 2019 ([H.R. 36](#)), which would establish an interagency working group led by the director of the White House Office of Science and Technology Policy (OSTP), with representatives from each federal science agency with an extramural research expenditure over \$1 billion and the Department of Education. The working group would be tasked with developing a uniform set of policy guidelines to address sexual harassment in science. The bill also directs the National Science Foundation (NSF) to commission a National Academies report on the influence of sexual harassment at higher education institutions on career advancement and authorizes NSF to award grants in order to study the causes and implications of sexual harassment for individuals in science. Senator Kamala Harris (D-Calif.) April 8 introduced the companion bill to H.R. 36 in the Senate ([S. 1067](#)).

Upcoming Hill Briefings and Other Events

8. NASEM Meeting on Clinical Use of Human Genome Editing – August 13

The National Academies of Sciences, Engineering, and Medicine (NASEM) is hosting the [first meeting](#) of the International Commission on Clinical Use of Heritable Human Genome Editing from 8:30 am – 5:15pm on August 13 in Washington, D.C. The goal of this commission is to "develop a framework for scientists, clinicians, and regulatory authorities to consider when assessing potential clinical applications of human germline genome editing...if society concludes that heritable human genome editing applications are acceptable." [Registration](#) is required to attend the event in person or to view the webcast.

9. Rally for Medical Research – September 18-19

Join a broad coalition of stakeholders representing millions of patients and other advocates from the medical research advocacy community on September 18-19, 2019, for the next Rally for Medical Research Hill Day and help raise awareness of the urgent need for continued investment in the NIH to improve health, spur more progress, inspire more hope, and save more lives. Please visit the [event website](#) for more information and to register. Registration closes August 30.

10. NIH Fall Regional Seminar – Nov. 6-8

The NIH is hosting the Fall 2019 NIH Regional Seminar on Program Funding and Grants Administration in Phoenix, AZ, from Wednesday, Nov. 6- Friday Nov. 8. Visit the [website](#) to learn more about the program and to [register](#). Early registration rates apply through June 30.

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.