Ad Hoc Group Weekly Round Up – September 5, 2017

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 welcome suggestions from the community for future issues of the Weekly Round Up. Here's this week's featured tweet:

Rally for Medical Research (@RallyForNIH)

Can't make it to DC? Sign up to join the #RallyMedRes National Day of Action from anywhere in the US! http://TinyURL.com/RallyNDA

1. Senate Appropriations Committee Schedules Subcommittee and Full Committee LHHS Markup

The Senate Labor-HHS-Education Appropriations Subcommittee <u>scheduled</u> a markup of its FY 2018 Labor-HHS spending bill for Wednesday, Sept. 6 at 11am in 124 Dirksen Senate Office Building. Additionally, the Senate Appropriations Committee <u>scheduled</u> a full committee markup of the FY 2018 Labor-HHS spending bill for Thursday, Sept. 7 at 10:30am in 106 Dirksen Senate Office Building. Please note that the webcast of both markups will be audio-only.

2. House Rules Committee Tees Up LHHS Appropriations Bill for Floor Vote

Ahead of floor action, the House Rules Committee is <u>scheduled</u> to meet on Tuesday, September 5 at 5pm to consider the remaining appropriations bills, including the House version of the Labor-HHS bill. Over the August recess, the committee sent a "dear colleague" <u>letter</u> requesting amendments to H.R. 3354, the Department of the Interior, Environment, and Related Agencies Appropriations Act, 2018, also known as the Make America Secure and Prosperous Appropriations Act, 2018, which will be the legislative vehicle for the remaining House funding bills. According to House Majority Leader Kevin McCarthy's <u>weekly schedule</u>, the House is expected to act on the spending bills on the House floor as early as Wednesday, Sept. 6. The House Appropriations Committee <u>approved</u>, 28-22, its House Labor-HHS funding bill July 19, including a nearly \$1 billion increase for the NIH.

3. Open Mike: NIH's Next Generation Researchers Policy Now Posted

On Aug. 31, NIH's Deputy Director for Extramural Research Mike Lauer, MD, <u>posted</u> an article announcing that the NIH <u>plan</u> for the <u>Next Generation Researchers Initiative</u> (NGRI) is now available. The notice announces that the NGRI policy "will require institutes and centers to prioritize awards that will fund Early Stage Investigators and Early Established Investigators," which NIH describes as consistent with directives in the 21st Century Cures Act. For any inquiries, please email the Office of Extramural Research at MIHTrain@mail.nih.gov.

4. LA Times Op-Ed: Why the Federal Government Urgently Needs to Fund More Cancer Research

On Sept. 5, Frank Lalli, founding editor of New West magazine and author of "Your Best Health Care Now" wrote an op-ed about his experience as a multiple myeloma patient benefitting from a recently FDA approved CAR-T treatment. Additionally, Mr. Lalli writes about the need to invest in medical research noting that "under Democratic and Republican administrations, the National Institutes of Health budget has been cut by 15.5%, after inflation. This has left far too little NIH money for basic research and prevention, including for oncology trials." The author describes how these cuts set back cancer research

and limit availability of clinical trials. He also writes, "If we do not invest in more research, there is a good chance that we could cede our leadership in biomedical innovation to China or other countries."

5. Washington Monthly: The Looming Decline of the Public Research University

In the Sept./Oct. issue of Washington Monthly, Jon Marcus, higher education editor at the Hechinger Report, a nonprofit, nonpartisan education news outlet based at Teachers College, Columbia University, details the recent struggles of public research institutions due to reduced federal support for research and what trimming back the investment means to universities in the Midwest. Marcus writes, "[U]niversity research is in trouble, and so is an economy more dependent on it than many people understand." He adds that "Federal funding for basic research—more than half of it conducted on university campuses like this one—has effectively declined since 2008, failing to keep pace with inflation. This is before we take into account Trump administration proposals to slash the National Science Foundation (NSF) and National Institutes of Health (NIH) budgets by billions of dollars more."

6. The Dominion Post Op-Ed:Raise Caps to guard scientific quests, progress

On Aug. 27, Eric Kelley, PhD, wrote guest commentary in The Dominion Post asking his peers to urge lawmakers to "agree on a bipartisan [budget] deal and raise the fiscal year 2018 spending caps." Dr. Kelly, an associate professor in the Department of Physiology and Pharmacology at WVU Health Science Center, says that research needs "stable, long-term financial support." He adds that "inadequate funding creates substantive uncertainty" and "significantly limits the career opportunities for the next generation of young scientists who represent our future success." The full op-ed is attached.

7. UD Professor: Urge Congress to Allow More Research Funding.

In an Aug. 24 op-ed, University of Delaware Professor William Farquhar calls on Congress to raise budgetary spending caps and increase federal funding for research. Dr. Farquhar, who is also a board member of the Federation of American Societies for Experimental Biology (FASEB) and the American College of Sports Medicine, notes that "The societal value of research supported by NIH is indisputable, and has helped the young, the old, and all ages in between." He also highlights the fact that in Delaware, "federally funded research from the NIH and the National Science Foundation (NSF) supports basic and clinical research at universities and hospitals," saying the investment in scientific funding "should not be a partisan issue."

8. Golden Goose Awards – Sponsorship Deadline Approaching

The Golden Goose Awards, taking place on Sept. 27 at the Library of Congress, celebrate the stories of how basic research delivers major societal impacts – from NIH-funded massages for baby rats that changed how we treat premature babies (and saved billions in health care costs) to the once canceled NIH-funded adolescent health study that informs everything from school curricula to public health programs. Each year, three teams of researchers are showcased through written stories and documentary videos, and honored with an award ceremony in Washington, DC each fall. The award depends on the support of partners in the science community, and more than twenty different organizations in our community and beyond contribute each year. Attached are the 2017 Golden Goose Award Sponsorship opportunities (also on the Golden Goose Awards website). The deadline for sponsoring is Sept. 6.

9. Join the 2017 Rally for Medical Research Hill Day: Sept. 13-14

<u>Registration</u> for the Rally for Medical Research is now open. For five consecutive years, the Rally for Medical Research Hill Day has raised awareness during a critical time about the urgent need for an

increased investment in the NIH to improve health, spur more progress, inspire more hope and save more lives. The Rally for Medical Research Hill Day is scheduled to take place on Thursday, Sept. 14, in Washington, DC. A reception will take place on Wednesday, Sept. 13 on Capitol Hill from 5:30 to 7:30 pm following a Hill Day training session at 3:00 pm at the <u>Grand Hyatt</u>. Additionally, a hotel room block has been reserved on a first come, first served basis at the Grand Hyatt, Washington DC. Specific questions may be directed to <u>info@rallyformedicalresearch.org</u> and for organizations interested in sponsoring the event, more information is available at: http://rallyformedicalresearch.org/Pages/Hill-Day-Sponsors-2017.aspx. Follow the Rally on Twitter @RallyforNIH or join the group on Facebook https://www.facebook.com/RallyMedRes/

10. Alliance for Eye and Vision Research Congressional Luncheon Briefing

On Sept. 13 from noon to 1:15pm in G-2043 Rayburn House Office Building, the Alliance for Eye and Vision Research will host a briefing that to kick off the Third Annual Emerging Vision Scientists Day on Capitol Hill, held during International AMD Awareness Week 2017 and Healthy Aging Month. The briefing, titled, "Advances in the Treatment of Age-Related Macular Degeneration (AMD) and Retinal Diseases," will feature Mandeep Singh, MD, PhD, assistant professor of ophthalmology at the Wilmer Eye Institute at Johns Hopkins University. To RSVP for the briefing, contact Dina Beaumont by phone at 202-407-8325 or by email at dinabeau@aol.com. All luncheon briefing attendees and their colleagues are invited to attend the EVS Poster Reception, held on the evening of September 13 from 5:30-7:30 pm in Rayburn 2168 (Gold Room). More information attached.

11. AACR Cancer Progress Report 2017 Release

On Sept. 13, American Association for Cancer Research (AACR) will release its Cancer Progress Report 2017 at noon on Capitol Hill in 485 Russell Senate Office Building. The annual AACR Cancer Progress Report to Congress and the American public, now in its seventh edition, is a cornerstone of the efforts of the AACR to educate the public about cancer and the importance of biomedical research, as well as to advocate for increased federal funding for the NIH, NCI, and FDA. This year's report chronicles how federally funded research continues to improve lives, and it shows that our ability to fully capitalize on our ever-growing knowledge of cancer is dependent on robust, sustained, and predictable federal funding. The report highlights how recent advances across the clinical cancer care continuum, in particular immunotherapy and molecularly-targeted therapies, are helping cancer patients and their families. This year's report also focuses on the continued challenges we face in addressing cancer health disparities. Lunch will be provided at this widely attended event. Please RSVP for this event by September 8 by emailing govrelations@aacr.org.

12. NSABB Workshop on Policy for Institutional Oversight of Life Sciences Dual Use Research of Concern

On Sept. 25-26, the NIH and the National Science Advisory Board for Biosecurity (NSABB) will co-host a workshop to engage with stakeholders and facilitate information sharing among research institutions regarding their approaches to, and experiences with, implementing the <u>United States Government Policy for Institutional Oversight of Life Sciences Dual Use Research of Concern (DURC)</u>.

This two-day workshop will involve discussions with diverse institutional representatives and facilitate the sharing of experiences including strategies, best practices, challenges, and solutions regarding policy implementation and the identification and management of DURC. While webcasting will not be available, the meeting will be recorded for future viewing on the OSP Website. For additional details and to register please visit the workshop website. Email Kevin Ramkissoon (ramkissoonkr@od.nih.gov) for questions.

13. 14th Annual AERA Brown Lecture In Education Research with Alfredo J. Artiles

The American Educational Research Association (AERA) invites you to its <u>Annual Brown Lecture in Education Research</u>. This lecture is designed to feature the important role of research in advancing understanding of equality and equity in education. This year's featured speaker is Alfredo Artiles, PhD, dean of graduate education and the Ryan C. Harris professor of special education at Arizona State University. Dr. Artiles is a leading scholar on understanding and addressing educational inequities related to the intersections of disability with other sociocultural differences. The lecture will take place from 6 to 9 p.m. ET on Oct. 19 at the Ronald Reagan Building & International Trade Center (1300 Pennsylvania Ave NW Washington, DC). You may RSVP at https://www.eventbrite.com/e/14th-annual-aera-brown-lecture-in-education-research-tickets-35522375381?aff=email072717. This event is free and open to the public. A buffet reception will follow.

14. SfN Invites You to Its Neurobiology of Disease Workshop

On Nov. 10, The Society for Neuroscience (SfN) will host a 2017 Neurobiology of Disease Workshop, "Gene Therapy to Address Unmet Needs in Neurology." This workshop will feature Florian Eichler, MD, Xandra O. Breakefield, PhD, and others to discuss the breadth of current and emerging gene therapy approaches to treat neurologic disorders such as Alzheimer's disease, ALS, or muscular dystrophy. This workshop embraces the breadth of "gene therapy" including viral vectors, oligonucleotides, and cell therapies used in promising preclinical studies and clinical trials for a variety of neurologic disorders long thought to be incurable. These new methods involve DNA engineering, gene replacement using virus vectors and the patient's own genetically modified cells, oligonucleotides that can "revive" beneficial gene functions or suppress toxic ones, and viruses and cells armed to tackle brain tumors. For question, please email training@sfn.org.

15. FasterCures Convenes "Partnering for Cures" in San Francisco

Since 2009, <u>Partnering for Cures</u> (P4C) has been convening leaders with the experience, creativity, and motivation needed to transform the medical research system. The event is convened annually by <u>FasterCures</u>, a center of the Milken Institute, and connects decision-makers from across diseases who are motivated by the same mission – to reduce the time and cost of getting new therapies from discovery to patients. *FasterCures* is taking P4C on the road and convening a smaller, cross-sector group of medical research leaders in San Francisco. Registration is now open for P4C San Francisco on Nov. 14. Find out more information at http://www.partneringforcures.org/.

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 Joe Bañez at jbanez@aamc.org or Tannaz Rasouli at trasouli@aamc.org.