

Ad Hoc Group Weekly Round Up – October 23, 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:

Mira Sorvino (@MiraSorvino)

Why we push for @NIH \$ 2find a CURE 4 #metastaticbreastcancer #stageivstampede #diein, 113 reasons/day: "angels" #stageivneedsmore @METUPorg <https://twitter.com/MiraSorvino/status/920319384819679232>

1. House Labor-HHS Subcommittee Holds Two Hearings Related to Research

On Oct. 24, the House Appropriations Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) Subcommittee [will hold](#) an oversight hearing on “The Role of Facilities and Administrative Costs in Supporting NIH-Funded Research.” This hearing will take place at 10am in 2358-C Rayburn House Office Building. Additionally, the Labor-HHS Subcommittee [will hold](#) a hearing entitled, “Down Syndrome: Update on the State of the Science and Potential for Discoveries Across Other Major Diseases.” This hearing will take place on Oct. 25 at 10am in 2358-C Rayburn House Office Building.

2. NCI Director Sworn in to Office

On Oct. 18, the NIH [announced](#) that Norman E. “Ned” Sharpless, MD, took the oath of office on Oct. 17 to become the 15th director of the National Cancer Institute (NCI). Dr. Sharpless takes over for Douglas R. Lowy, MD, who was NCI’s acting director since April 2015. According to the NIH release, Dr. Sharpless comes to NCI from the University of North Carolina School of Medicine, Chapel Hill, where he served as director of the NCI-Designated Lineberger Comprehensive Cancer Center and as the Wellcome Distinguished Professor in Cancer Research.

3. FASEB President Thomas Baldwin Writes Op-Ed in The Hill

On Oct. 16, Tom Baldwin, PhD, president of the Federation of American Societies for Experimental Biology (FASEB) [wrote](#) an op-ed entitled, “21st century investments in science and education will ensure our ability to compete.” In the piece, Dr. Baldwin celebrates the recent Nobel Prize announcements and makes the point that Congress must continue investing in research to ensure that U.S. competitiveness is retained.

4. Briefing on the Intersection of Substance Abuse, Injuries & Violence – Oct. 24

On Oct. 24, the Injury and Violence Prevention Network, a coalition of national organizations working to advance injury and violence prevention, is hosting a congressional briefing on the intersection of substance abuse, injuries, and violence. The briefing discussion will have a specific focus on the impact on rural communities. This briefing will take place from 10 to

11:30am in the Capitol Visitors Center, congressional meeting room north, CVC-268. To RSVP, please email paul.bonta@safestates.org. See the attached flyer for more info.

5. The Friends of NIAAA Briefing on Treatment Navigator – Oct. 30

Approximately 15 million adults in the United States have alcohol use disorder (AUD), yet only a minority of them—less than 10 percent—receive any treatment. Although there are many evidence-based AUD treatment options available, including professionally-led behavioral interventions and FDA-approved medications, finding quality care can be confusing. To highlight a helpful tool, the Friends of NIAAA is hosting a briefing on Oct. 30, to discuss National Institute on Alcohol Abuse and Alcoholism (NIAAA)'s new Alcohol Treatment Navigator. This lunch briefing will take place from 12 to 1:30pm in 2226 Rayburn House Office Building. Fill out this [online form](#) to RSVP and email Cynthia Malley at cmalley@apa.org for questions. More info in the attached flyer.

6. Cancer Research Symposium Hosted by Johns Hopkins – Nov. 1

Please join Johns Hopkins School of Medicine for a symposium in 902 Hart Senate Office Building in Washington, D.C., on Wed., Nov. 1, from 8:30 a.m. to noon to hear from top scientists on how they recommend expanding and implementing the Blue Ribbon Panel's road map for cancer research. The speakers will discuss a report that will be published by the journal *The Lancet Oncology* and is co-edited by Elizabeth Jaffee, M.D., deputy director of the Johns Hopkins Kimmel Cancer Center, and Chi Van Dang, M.D., Ph.D., scientific director at Ludwig Cancer Research and professor at The Wistar Institute. Learn what you need to know about investing in research, prevention and treatment of cancer, the second leading cause of death in the U.S. RSVP for the symposium by emailing JHonthRoad@jhmi.edu. See the attached flyer for more info.

7. AEVR Briefing on National Keratoconus Day – Nov. 7

The Alliance for Eye and Vision Research (AEVR) invites you to a luncheon briefing recognizing National Keratoconus Day 2017, which falls on Nov. 10. The briefing, entitled, "Spearheading Keratoconus Research: A Quest for Novel Treatments," will take place on Nov. 7 from 12 to 1:15pm in 2075 Rayburn House Office building. To RSVP, call Dina Beaumont 202-407-8325 or email dinabeau@aol.com. See the attached flyer for more info.

8. SfN Workshop on Neurobiology of Disease – Nov. 10

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 questions, please email training@sfn.org.

9. Global Liver Institute "Advanced Advocacy Academy"– Nov. 10-11

Even though half a billion people are affected with liver disease world-wide, awareness for liver diseases is low. Knowing that patients often have some of the most valuable perspectives on health care, the [Global Liver Institute](#) has designed a two-day workshop to train patients and family members to take the knowledge they have gained from their health care experiences and use it to have an impact through advocacy. With the help of expert patient advocates, policy-makers, physicians, and communicators, participants are offered the opportunity to gain skills from multiple learning tracks, including legislation, drug development, patient-centric value frameworks, health care delivery and media to cater to the different skill-sets and interests. Find out more at globalliver.org/advanced-advocacy-academy.

10. FasterCures “Partnering for Cures” in San Francisco – Nov. 14

Since 2009, [Partnering for Cures](#) (P4C) has been convening leaders with the experience, creativity, and motivation needed to transform the medical research system. The event is convened annually by [FasterCures](#), 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/>.

10. Job Announcement - HIVMA Hiring Senior Advocacy and Policy Manager

The HIV Medicine Association (HIVMA) is searching for a Senior Advocacy and Policy Manager who will lead HIVMA policy and advocacy efforts on key issue areas, including federal appropriations for HIV related programs, biomedical research, HIV criminalization, system and payment reform, and promoting science-based prevention and public health. For more information on the position, please visit <https://infectious-diseases-society-of-america.hiringthing.com/job/52141/senior-advocacy-and-policy-manager>

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.