Ad Hoc Group Weekly Round Up
August 2, 2021

The Weekly Round Up will be on hiatus while Congress is in recess during the month of August.

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:

@RallyForNIH Rally for Medical Research – August 2
According to @UMR4NIH, @NIH research contributed 536,000 jobs and $91.35B to the economy in FY 20. The NIH saves lives and grows the economy. On September 23, we are rallying for groundbreaking research. Register now: https://bit.ly/3igZe0P #RallyMedRes #FundNIH

House Passes FY 2022 Labor-HHS Bill
The House of Representatives passed its FY 2022 Labor-HHS spending by a vote of 219-208 on July 29 as part of H.R.4502, a package of seven spending bills. The House completed consideration of amendments to the Appropriations Committee-passed Labor, Health and Human Services, Education, and Related Agencies spending bill on July 27, providing $3 million more than the committee-passed bill for specific NIH institutes and centers, for a total NIH budget of $49.4 billion.

Following passage of the seven-bill package, the AAMC-convened Ad Hoc Group for Medical Research issued a statement applauding the House for its continued commitment to the NIH and urging the Senate to work quickly on its own bipartisan proposal to increase funding to the NIH.

The Biden administration issued a Statement of Administration Policy for H.R. 4502, noting support for passage of the bill while expressing disappointment at the $3 billion provided for ARPA-H in the House-passed bill, compared to the administration’s requested $6.5 billion. The Congressional Research Service also published a report on the status of the FY 2022 Labor-HHS spending bill.

Federal Officials Testify Before House E&C on Neurodegenerative Diseases
Institute directors from the NIH testified before the House Energy & Commerce Health subcommittee on July 29 in a hearing titled The Path Forward: Advancing Treatments and Cures for Neurodegenerative Diseases.” Richard Hodes, MD, director of the National Institute of Aging and Walter Koroshetz, MD, director National Institute of Neurological Disorders and Stroke, discussed the burden of neurodegenerative diseases and updated members about research advances to development treatments and prevention strategies for these diseases, including Alzheimer’s and related dementias and amyotrophic lateral sclerosis (ALS).

2021-2025 NIH-Wide Strategic Plan
The NIH issued its 2021-2025 NIH-Wide Strategic Plan to guide NIH research efforts over the next five years. Building on the previous plan, the new plan seeks to advance the vision for biomedical research direction, capacity, and stewardship with a focus on five cross-cutting themes: improving minority health and reducing health disparities; enhancing women’s health; addressing public health challenges across the lifespan; promoting collaborative science; and leveraging data science for biomedical discovery.

The Strategic Plan was developed through a collaborative process involving leadership and staff across the NIH and informed by input from key stakeholders, including the research community, professional societies, advocacy groups, and the public, via a request for information.

Learn more via the NIH-Wide Strategic Plan website.

Factsheets: Genomic Data Sharing in NIH-Funded Research
NIH's National Human Genome Research Institute (NHGRI) is dedicated to advancing human health through genomics. The Human Genome Project, which was led by the NHGRI, enabled more sharing of genomic data which caused researchers and the public to become uncertain of the consequences of making these data freely available to the research community. To address these concerns, NHGRI continues to fund research into the ethical, legal, and social implications of genomic data sharing, and the NIH is continually considering both the benefits and risks of these practices.

NHGRI recently released two factsheets on genomic data sharing. The one-pager gives an overview of the institute, genomic data, and its use in research. The extended factsheet gives more detail into how genomic data is protected and the importance of international data sharing.

UMR Fact Sheet: Why Invest in NIH?
United for Medical Research will be sharing a series of five fact sheets that highlight why it is important that the United States maintain a strong investment in the NIH. This first fact sheet on responding to COVID-19 focuses on the critical role of past, present, and future investments in the NIH and the global effort to address COVID-19. Additional fact sheets will be shared as they become available. For more information on the efforts on UMR members to prevent, treat, and eradicate COVID-19, visit their COVID-19 resources page.

Upcoming Events

NIH and OSTP Listening Sessions on ARPA-H – August 3
The National Institutes of Health and the White House Office of Science and Technology Policy are organizing a series of listening sessions to get feedback from patient advocacy groups, industry, scientific professional organizations, and other stakeholders on the president’s ARPA-H proposal. These listening sessions will vary in format from broad, public discussions to smaller, invitation-only meetings to discuss more sensitive information.

The next three sessions are detailed below:

**Session 6**: This meeting will convene stakeholders in the areas of diabetes, digestive disorders and kidney disease, child and maternal health, complementary and integrative medicine (August 3).

**Session 7**: This meeting will convene stakeholders in the areas of biomedical research, translational research and general medicine (August 4).

**Session 8**: This meeting will convene stakeholders in the areas of biomedical research, translational research and general medicine (August 4).

**NIA, NICHD, & NHLBI Science of Sleep Facebook Live Q&A Series**

National Institute of Aging is collaborating with the Eunice Kennedy Shriver National Institute on Child Health and Human Development and the National Heart, Lung, and Blood Institute on a Science of Sleep Facebook Live Q&A series. The effort is designed to raise awareness about the importance of sleep across the lifespan, highlight NIH research in this area, and promote evidence-based strategies for improving sleep at every age. The following segments are planned:

- **The Science of Sleep and Teens** on Tuesday, Aug. 10, 2:30pm ET
- **The Science of Sleep and Adults** on Tuesday, Aug. 17, 2:30pm ET
- **The Science of Sleep and Older Adults** on Tuesday, Aug. 24, 2:30pm ET

**Apply for National Eczema Association Research Grants – Deadline August 31**

Applications are being accepted for the 2021 National Eczema Association (NEA) research grant cycle. Grants for junior and senior investigators ranging from $5,000-$150,000 are available. Applications are due August 31. Additional details are on the NEA website.

**Virtual Rally for Medical Research - September 22-23**

The Rally for Medical Research is held every September and includes more than 300 national organizations coming together to call on our nation’s policymakers to make funding for National Institutes of Health (NIH) a national priority and raise awareness about the importance of continued investment in medical research that leads to more progress, more hope, and more lives saved. This year’s event will be held virtually on September 22-23. For more information to register, please visit rallyformedicalresearch.org.

**Requests for Public Comment**

**Public Comment on Proposed National Priorities for Health – August 27**
PCORI’s work is guided by a set of national priorities and a research agenda that provide a framework for our funding of patient-centered comparative clinical effectiveness research. Beginning in 2020, we embarked on a strategic initiative to identify new priorities to direct our work in the years ahead.

In the latest step in this process, our Board of Governors at its June meeting approved posting for public comment five proposed National Priorities for Health developed in consultation with hundreds of stakeholders, advisors, and experts. We invite your comments on the proposed National Priorities for Health during the public comment period June 28 to August 27 and look forward to sharing an overview of the proposed national priorities on a June 29 webinar.

**NIH Seeks Input on New Resource for Developing Consent Language for Future Use of Data and Biospecimens – September 29**

The NIH is requesting information from stakeholders on the utility and useability of a resource that includes sample language and points to consider when developing informed consent documents for data and biospecimen sharing (NOT-OD-21-131). Stakeholder feedback on this resource will be essential in ensuring this resource is maximally useful to the community. NIH emphasizes that any use of the sample informed consent language would be completely voluntary and will not be required.

The comment window is open for 90 days and NIH has established a web portal for responses (https://osp.od.nih.gov/rfi-comment-informed-consent-sharing/). To ensure consideration, comments must be received no later than September 29, 2021. Questions may be sent to SciencePolicy@mail.nih.gov.

**NIH COVID-19 Resources**

- [NIH COVID-19 resource for applicants and grantees](https://www.nih.gov) including guidance for various aspects of research and grant application processes, as well as FAQs and COVID-19 funding opportunities.

- [COVID-19 “Updates History” webpage](https://www.nih.gov) that details relevant updates for applicants and grantees by date.

- [FAQ document on COVID-19 flexibilities](https://www.nih.gov) related to policies and programs affecting the grants process.

- [Funding opportunities specific to COVID-19](https://www.nih.gov) lists active and expired funding opportunities across NIH related to SARS-CoV-2/COVID-19 research.

- [NIH COVID-19 Research Website](https://www.nih.gov) provides a central location for trusted, up-to-date, accurate information about NIH research and our strategic role in COVID-19 research.

- [HHS COVID-19 awards tracking website](https://www.nih.gov) including data on awards made by all HHS awarding agencies with supplemental appropriations.
Combat COVID website including information for those who have never had COVID-19, have been infected, have recovered, and for health care providers.

Job Postings

The Director, Government Affairs and Policy, The ALS Association
The Director, Government Affairs reports to the Vice President, Public Policy and works as part of a team with the Associate Director of Grassroots Advocacy and the Public Policy Manager. The Director, Government Affairs designs and directs all aspects of government affairs including identifying legislative and regulatory opportunities, securing appropriations, and advancing legislation and policies through nonpartisan advocacy with members of Congress, congressional committees, and relevant federal agencies. The Director, Government Affairs is also responsible for collaborating with the Associate Director of Grassroots Advocacy to mobilize Association chapters and volunteers to achieve results and represents the association in national coalitions focused on the needs of people living with ALS. Bachelor’s degree with 4-8 years of work experience in healthcare government affairs and advocacy or the equivalent combination of education and work experience. Click here to apply.

ACS CAN Seeks Legislative Director, Federal Relations
The American Cancer Society Cancer Action Network (ACS CAN) is seeking a Legislative Director in their Advocacy Department. They will serve as principal federal lobbyist and strategist for the Society and ACS CAN on all issues relating to research, annual federal appropriations, early detection, prevention of cancer, and other related issues. The candidate must have high level expertise in federal health policy and must also have 15 or more years of professional experience, including extensive legislative and/or advocacy experience. Bachelors or master's degrees and Capitol Hill experience are preferred. Additional details and application instructions are here.

APA Seeks Senior Directors, Congressional and Federal Relations
The American Psychological Association (APA) Advocacy Office is recruiting for two Senior Directors of Congressional and Federal Relations. Both positions focus primarily on science government relations: to serve as liaisons for federal science funding agencies, cover science policy issues and represent APA in coalitions and partnerships (portfolios to be determined). One of the positions is Masters degree preferred; the other is doctoral degree preferred. You can apply via the APA Jobs gateway.

ASM Seeks Senior Specialist, Regulatory Affairs
The American Society for Microbiology (ASM) is seeking a Senior Specialist, Regulatory Affairs. The Senior Specialist will play an integral role on ASM’s federal affairs team by monitoring, analyzing and reporting on regulatory activity that has the potential to affect the microbial sciences community in assigned policy areas, with a particular focus on diagnostic regulation, food safety, coding and reimbursement. The specialist will also identify opportunities for ASM federal policy engagement with regulatory agencies such as the FDA and CMS, and help build relationships with agency officials. For more information go here.

IADR/AADR Seek Assistant Director of Government Affairs
The International and American Associations for Dental Research are seeking an Assistant Director of Government Affairs to recommend and implement the Associations’ policy priorities related to dental, oral and craniofacial research; the federal research enterprise, including the scientific workforce; scholarly publishing; international collaboration and more. Additional information and application instructions can be found here.

NHLBI Seeks Science Policy Analyst
NIH’s National Heart, Lung, and Blood Institute (NHLBI) seeks a Science Policy Analyst to assist in the institute’s engagement with Congress. The analyst’s role will include reviewing proposed legislation, responding to Congressional inquiries, preparing public outreach materials, and more. Additional information and instructions for applying can be found here.

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.