NAEVR Comments Regarding 21st Century Cures 2.0 (H.R. 6000)

December 16, 2021

The Honorable Diana DeGette
The Honorable Fred Upton

Dear Congresswoman DeGette and Congressman Upton:

On behalf of the vision research community, the National Alliance for Eye and Vision Research (NAEVR) thanks you for your continued leadership and support of issues related to medical research and innovation. NAEVR, which serves as the privately funded “Friends of the National Eye Institute (NEI),” is a 501c4 coalition comprised of 50 organizations involved in eye and vision research, including ophthalmic/optometry professional societies, patient and consumer groups, private funding foundations, and industry.

Background

In 2016, NAEVR endorsed the 21st Century Cures Act noting that, “since vision loss is a co-morbid condition of numerous disease and conditions, we strongly support the Act’s creation of the National Institutes of Health (NIH) Innovation Fund as a means to fund life-saving and life-enhancing research through the large-scale NIH-wide initiatives.” Vision researchers have especially benefitted from funding opportunities in BRAIN and Regenerative Medicine initiatives, in addition to NEI funding.

In July 13, 2021, comments on a Cures 2.0 discussion draft, NAEVR requested that the proposed Advanced Research Projects Agency-Health (ARPA-H) engage all NIH Institutes and Centers (I/C) in offering up their best ideas for rapid translation, while urging authorizers to work with appropriators to ensure that ARPA-H investments are balanced with robust investment in the NIH “base” to support investigator-initiated research. NAEVR also supported inclusion of the Research Investment to Spark the Economy (RISE) Act for research recovery. While recognizing that all researchers were impacted by clinical and laboratory shutdowns and slowdowns, early-stage investigators seeking their first NIH R01 grant were especially affected, as documented in a July 1, 2021, JAMA Ophthalmology article in which Emerging Vision Scientists spoke about the pandemic's impact on their career pathway, at the link below: https://jamanetwork.com/journals/jamaophthalmology/fullarticle/2781696

Comments on H.R. 6000

As in its prior submission, NAEVR will confine its comments to the “Research” section of the bill.
ARPA-H
NAEVR participated in several of the “Listening Sessions” presented by the White House Office of Science and Technology Policy (OSTP) and the NIH, including the July 26 Eye Disease, Deafness, and Dental Session and the October 20 Listening Session on the Summary Report. NAEVR agrees with several of the “guiding principles” that were set forth in these calls from a consensus of the participants, as described by OSTP/NIH, that includes ARPA-H:

- Centering around technologies rather than specific diseases, such that it can be applied to solve disease-specific problems, and complementing NIH’s research portfolio, not duplicating it.
- Using data sharing platforms and universal data standards and systems
- Engaging the stakeholder community
- Embracing equity and diversity as a cornerstone of ARPA-H’s mission (from diversity in staffing to developing technologies that recognize health differences and disparities).

OSTP/NIH also recognized a consensus from participants that investment in ARPA-H should supplement, not supplant, funding for NIH’s base. As noted in prior comments, even with the six years of above-inflation NIH funding increases, most I/Cs have not kept up with biomedical inflation—NEI’s purchasing power in FY2021 is less than that in FY2012.

Although much of the bill’s language regarding ARPA-H deals with its organization and structure, NAEVR encourages legislative staff to “crosswalk” how that language ultimately ensures implementation of the guiding principles so that ARPA-H fully meets its anticipated mission.

RISE Act Inclusion/Research Recovery
Since the RISE Act was introduced, Congress has passed legislation that focuses on pandemic-related research and public health issues, in addition to economic recovery. However, the recent Infrastructure Investment and Jobs Act (H.R. 3684) and the still-developing Build Back Better legislation do not address research recovery.

Yet, between July 2020 and May 2021 in testimony before the Senate Labor, Health and Human Services, and Education (LHHS) Appropriations Subcommittee, NIH Director Francis Collins, MD, PhD acknowledged that his initial estimate of a $10 billion loss to the research enterprise had risen to $16 billion. How much greater will this impact on the NIH research enterprise grow—as well as that at other federal scientific agencies—in terms of economic loss and impact on researcher career pathways? Congress should ensure research recovery relief, and NAEVR applauds inclusion of the RISE Act in this important Cures 2.0 legislation.

Thank you for considering NAEVR’s comments, and we look forward to working with you as the process moves forward.

Sincerely,

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