

THE AD HOC GROUP FOR MEDICAL RESEARCH

July 16, 2021

The Honorable Diana DeGette United States House of Representatives Washington, DC 20515

The Honorable Fred Upton United States House of Representatives Washington, DC 20515

Dear Representatives DeGette and Upton:

On behalf of the Ad Hoc Group for Medical Research, thank you for your continued leadership and support of issues related to medical research and innovation. The Ad Hoc Group for Medical Research is a coalition of nearly 400 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry dedicated to enhancing federal investment in biomedical, behavioral, social, and population-based research at the National Institutes of Health (NIH).

We write today in response to the release of the 21st Century Cures Act 2.0 (Cures 2.0) discussion draft and the accompanying Request for Information (RFI) on the Advanced Research Projects Agency for Health (ARPA-H) proposal. Our community appreciates the opportunity to comment on the discussion draft and looks forward to working with you to ensure that the final Cures 2.0 legislation advances health innovation while balancing the need to invest in foundational medical research. While the individual organizations that make up the Ad Hoc Group likely will be submitting comments on several aspects of the bill and the RFI, as a coalition focused exclusively on NIH appropriations, we have directed our comments in this letter specifically to Title V of the discussion draft and the funding questions in the RFI.

Sec. 501. Advanced Research Projects Agency for Health

The Ad Hoc Group continues to be grateful for Congress's commitment to medical research, and we commend President Biden's proposed overall \$52 billion investment in the NIH in fiscal year (FY) 2022. President Biden's call to create ARPA-H holds the promise of new approaches to research and development (R&D) that could accelerate biomedical innovation and deliver more cures and treatments for targeted diseases. ARPA-H's success, however, depends on continued robust support for the fundamental medical research already within NIH's purview. Congress wisely has advanced six years of above-inflation increases for NIH after over a decade of effectively flat funding. While this bipartisan support has been essential in helping the agency recover some of its lost purchasing power after the end of the "doubling" in 2003, the NIH overall still is able to fund only 1 in every 5 promising proposals, with some institutes, such as the National Cancer Institute, limited to approximately 1 in every 9. Additionally, because many of the recent increases have been concentrated in targeted initiatives, growth across the agency has been uneven. There is no question that we are leaving transformative, potentially life-saving science on the table under NIH's current formation, simply as a function of funding.

As you consider how to establish ARPA-H, the Ad Hoc Group urges you to work with appropriators to ensure that investments in ARPA-H are balanced with robust investment in NIH-supported, foundational, investigator-initiated research that forms the bedrock of our nation's medical research ecosystem at labs across the country. There is room in this ecosystem for both advanced R&D approaches like ARPA-H and foundational science that is the core of NIH's mission, but – critically – the former depends on the latter. NIH is the worldwide gold standard for support of fundamental research and its tested methods – which have led to reductions in deaths from heart disease, cancer, stroke, HIV/AIDS, unintentional injuries, and other causes over the last several decades – will continue to support multiple areas in critical need of cures, treatments, diagnostics, and preventive interventions.

The Ad Hoc Group appreciates that the spending bill recently approved by the House Appropriations Committee includes \$49 billion overall for the NIH's base program level in FY 2022, and that it strikes the necessary balance between robust growth in NIH's foundational work and investment in ARPA-H. Establishing the appropriate firewalls to keep ARPA-H funding distinct from the existing NIH budget, including working with appropriators to explore alternative, dedicated funding mechanisms to support ARPA-H, will be key to prevent entangling the budgets and missions of the two agencies in ways that may be problematic.

Sec. 502. Research Investment to Spark the Economy

The Ad Hoc Group is immensely grateful for the inclusion of your bill, the Research Investment to Spark the Economy (RISE) Act, in the draft Cures 2.0 legislation. While the impacts of the COVID-19 pandemic were felt across the entire country and throughout the economy, the repercussions felt in the scientific research sector are likely to reverberate for years to come. Like in other scientific disciplines, a significant portion of the nation's medical research capacity was forced to shut down for at least some time during the pandemic, and when researchers returned to their laboratories it was at reduced capacity to adhere to necessary health and safety protocols. In response to a question at a recent Senate Labor-HHS-Education Appropriations Subcommittee hearing, NIH Director Francis Collins, MD, PhD, estimated the lingering financial impact from this lost research productivity at \$16 billion.

Addressing the pandemic's deleterious effects on the research workforce – especially hard-hit groups like women, underrepresented minorities, and early career scientists – repopulating cell and animal lines, and replacing equipment and supplies donated to hospitals and clinical centers are critically important to position the research enterprise to move forward instead of backwards. The emergency funding for federal research agencies, including NIH, in the RISE Act is an important step in ensuring that the nation's medical research ecosystem rebounds from the pandemic, and we applaud the bill's inclusion in the Cures 2.0 discussion draft.

Thank you for your continued commitment to patients, health, and medical research and for the opportunity to provide input on the Cures 2.0 discussion draft and the ARPA-H proposal. The Ad Hoc Group for Medical Research looks forward to working with you as the process moves forward.

Sincerely,

Tannaz Rasouli Executive Director