



THE AD HOC GROUP FOR MEDICAL RESEARCH

July 29, 2024

The Honorable Diana DeGette
U.S. House of Representatives
Washington, DC 20515

The Honorable Larry Bucshon
U.S. House of Representatives
Washington, DC 20515

Dear Representatives DeGette and Bucshon:

On behalf of the Ad Hoc Group for Medical Research, thank you for your efforts to ensure that a robust, sustained investment in medical research through the National Institutes of Health (NIH) remains a high national priority and for the opportunity to respond to your June 6, 2024, request for information. 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 the federal investment in biomedical, behavioral, social, and population-based research supported by NIH.

Our community is grateful for the longstanding bipartisan and bicameral efforts to strengthen the nation's investment in NIH. As you know, the federal commitment to robust and sustained funding for NIH has been essential in advancing medical research in the United States and setting in motion nearly every cure, treatment, diagnostic, and preventive intervention in practice today. Passage of the 21st Century Cures Act represented an important and transformative example of bipartisan recognition that our nation is stronger with a thriving medical research enterprise. We appreciate your ongoing commitment to building on that landmark legislation, and we welcome the opportunity to provide input as you consider the next phase.

While many of the coalition's member organizations are submitting comments in response to your RFI and other Congressional inquiries, providing feedback on most structural and policy reforms would be beyond the scope of the Ad Hoc Group for Medical Research. Because the sole focus of the Ad Hoc Group is enhancing the federal investment in NIH overall, our comments are concentrated primarily on the Innovation Account established in the Cures legislation, which was intended to supplement NIH's annual appropriation and allow NIH to support specific large-scale initiatives without redirecting resources from other existing and emerging fields of study. In addition to the new resources that the Account infused, the benefit of this model has been predictability in funding over the course of several years for the specific initiatives that the Account has supported. Given the long-term nature of scientific discovery and medical research and the disruptive effect of unreliable funding, the stability such an approach has offered has been welcome.

As you consider the next phase of the Cures Initiative, we offer the following observations to enhance the novel funding approach that Cures established. While the funding has been immensely helpful, the dramatic fluctuations in resources from year to year posed challenges in developing a consistent trajectory for multi-year projects. Minimizing such fluctuations would prevent artificial stops and starts that are inconsistent with the NIH peer review and research processes and would help optimize planning for how the funds could be used. Additionally,


though the intent was for the Innovation Account to supplement the annual appropriation to NIH, constrained federal discretionary spending limits resulted in a situation where Cures funding has been used to compensate for inadequate spending allocations for the Labor-HHS-Education Appropriations spending bills. While the additional resources were essential in supporting the agency in these circumstances, the fluctuations put additional pressure on appropriators to backfill funding levels in years when funding in the Innovation Account would dip.

Ultimately, the Innovation Account has been an asset to medical research. Our collective experience over the last decade will be beneficial in informing its next iteration, particularly as programs funded by the Account now are experiencing a 10-year funding cliff, which will cause research progress in specified areas to slow. The Ad Hoc Group supports efforts to reinvest in an Innovation Account going forward and looks forward to working with you to prevent any funding cliffs.

We appreciate your continued support of stable, meaningful growth above inflation across NIH, which positions the agency – and the patients who rely on it – to capitalize on the full spectrum of research from basic to translational, and across the breadth of discovery in the biomedical, behavioral, social, and population-based sciences. In addition to improving the health and well-being of patients nationwide, the ongoing success of the medical research enterprise also drives local and national economic activity, strengthens U.S. national security and global competitiveness, and inspires future generations of scientists to commit to careers in research.

Thank you again for your leadership and bringing hope of cures and reduced suffering to patients and their families.

Sincerely,

A handwritten signature in black ink, appearing to read 'Tannaz Rasouli'.

Tannaz Rasouli
Executive Director
The Ad Hoc Group for Medical Research