

# Congress of the United States

Washington, DC 20515

March 13, 2026

The Honorable Andy Harris, MD  
Chairman  
Agriculture, Rural Development and FDA  
Subcommittee  
Committee on Appropriations  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Sanford Bishop  
Ranking Member  
Agriculture, Rural Development, and FDA  
Subcommittee  
Committee on Appropriations  
U.S. House of Representatives  
Washington, DC 20515

Dear Chairman Harris and Ranking Member Bishop:

As you develop the Fiscal Year (FY) 2027 Agriculture, Rural Development, Food and Drug Administration (FDA), and Related Agencies Appropriations Act, we write to urge that you include funding and report language to support programs and initiatives that accelerate the development of treatments for rare diseases and conditions. Specifically, we ask that you include funding to enable the FDA's Rare Disease Innovation Hub to implement its strategic agenda.

After years of bipartisan advocacy from Congress and requests by the rare disease community, the FDA launched the Rare Disease Innovation Hub in late 2024. The Hub was created to strengthen collaboration on rare disease issues across all FDA Centers and review divisions, to drive more consistency in regulatory decision-making, and to efficiently build FDA staff expertise. The Hub's mission addresses challenges and gaps identified by rare disease patients and other key stakeholders, noting varying levels of expertise across Centers and inconsistent review standards.

After over a year of operation, the Hub has released its second strategic agenda, which builds on its accomplishments thus far. Current goals include initiatives to further strengthen the patient's role and perspective in therapy development and review, and to build on intra-FDA training programs to deepen reviewers' knowledge and exposure to the latest innovations and methods for assessing the efficacy of drugs to treat rare diseases. Yet without targeted and sustained resources, the Hub may be unable to fulfill these critical functions. **We urge you to appropriate \$5,000,000 to support the Hub, and to include the corresponding report language to provide additional guidance and direction.**

- *Rare Disease Innovation Hub – The Committee is pleased with the work of the FDA Rare Disease Innovation Hub in its first full year of operations including its launch of the RISE Workshop Series and its focus on improved alignment and coordination of rare disease activities across FDA functions. The Committee appropriates \$5,000,000 to support the Hub's work and implementation of its current strategic agenda, particularly actions to expand opportunities for patient and clinical community stakeholders to engage earlier and more fully in the therapy development, and to enhance implementation of efforts to support and sustain cross-center consistency on rare disease review standards.*

On behalf of the more than 30 million Americans living with rare diseases, thank you for considering the inclusion of this programmatic request and the following report language within the FY 27 Agriculture, FDA, and Related Agencies Appropriations bill. If you have any questions, please do not hesitate to contact us.

Sincerely,



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Gus M. Bilirakis  
Member of Congress



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Doris Matsui  
Member of Congress



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Diana DeGette  
Member of Congress



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Mike Carey  
Member of Congress



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Jake Auchincloss  
Member of Congress



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John Joyce, M.D.  
Member of Congress



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Michael T. McCaul  
Member of Congress



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Vern Buchanan  
Member of Congress



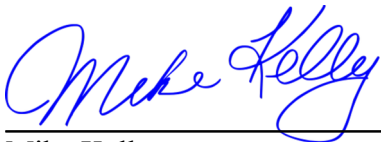
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Becca Balint  
Member of Congress



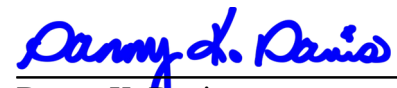
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Brian K. Fitzpatrick  
Member of Congress



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Mike Kelly  
Member of Congress



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Danny K. Davis  
Member of Congress



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Eleanor Holmes Norton  
Member of Congress



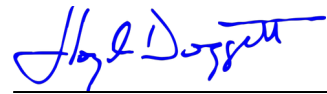
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Seth Magaziner  
Member of Congress



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Henry C. "Hank" Johnson, Jr.  
Member of Congress



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Lloyd Doggett  
Member of Congress



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Ilhan Omar  
Member of Congress



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Rashida Tlaib  
Member of Congress



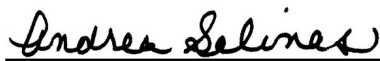
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Marilyn Strickland  
Member of Congress



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Raja Krishnamoorthi  
Member of Congress



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Andrea Salinas  
Member of Congress



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George Latimer  
Member of Congress



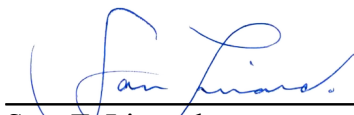
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Steve Cohen  
Member of Congress



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Kelly Morrison  
Member of Congress



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Sam T. Liccardo  
Member of Congress



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Lucy McBath  
Member of Congress



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Chris Pappas  
Member of Congress