



November 19, 2024

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The Honorable Mike Johnson
Speaker U.S.
House of Representatives
Washington, D.C. 20515

The Honorable Chuck Schumer
Majority Leader
U.S. Senate
Washington, D.C. 20510

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Mitch McConnell
Minority Leader
U.S. Senate
Washington, D.C. 20510

Dear Speaker Johnson, Leader Jeffries, Leader Schumer, and Leader McConnell:

On behalf of Research!America, thank you for all you and your respective staff members do to safeguard and promote the health and wellbeing of the American people. In that context, we urge you to take action before December 20, 2024 to reauthorize the [Rare Pediatric Disease \(RPD\) Priority Review Voucher \(PRV\) Program](#), an economic incentive that has made a marked difference in the outlook for children facing pain, disability, and death from individually rare, but collectively prevalent, diseases. An estimated 1 in 10 Americans have a rare disease, with children representing half or 15 million of the [total](#). Tragically, [30% of rare disease patients die before the age of 5](#).

The RPD PRV Program, which will expire on December 20, 2024, unless Congress acts, does not just offer hope, it delivers on it. Since first authorized in 2012, the RPD-PRV program has successfully enabled the development of [more than 50 treatments across 39 rare pediatric diseases](#).

By incentivizing investment in challenging-to-develop therapies, this program spurs new businesses and jobs, generates new export markets, and fosters the cutting-edge research, engineering, and manufacturing that gives our nation its competitive edge in the life sciences arena. But fundamentally, the RPD PRV program is important because it delivers answers for seriously ill children.

Please act as soon as possible before December 20 to reauthorize the RPD-PRV program. Its success has been, and will continue to be, a lifeline for children and a

desperately needed source of hope for their families. Thank you again for your leadership and for considering this request.

Sincerely,

A handwritten signature in cursive script that reads "Ellie Dehoney". The signature is written in black ink and is positioned above the typed name and title.

Ellie Dehoney
Senior Vice President, Policy and Advocacy
Research!America