Action Alert

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ALERT TEXT

Urge Your Member of Congress to Support the Reauthorization of the Rare Pediatric Disease PRV Program

Our fight to reauthorize the Rare Pediatric Disease PRV Program continues. Please join us in urging your members of Congress to reauthorize this critical program by passing the Give Kids a Chance Act of 2025 (H.R. 1262/ S. 932). The Creating Hope Act of 2012 established the PRV Program to help expedite the development and promotion of drugs for diseases that disproportionately affect children. Since then, the PRV Program has incentivized the development of 60 new treatment options. Its impact is undeniable as it has led to treatments for over 40 rare disease communities, including Spinal Muscular Atrophy (SMA), Sickle Cell Disease, Progeria Syndrome, and Rett Syndrome, which previously had no treatment options.

Progress has been made in the effort to extend the Rare Pediatric PRV Program, but Congress' job is not done yet. On September 23, 2024, the House unanimously passed the Give Kids a Chance Act which included the Creating Hope Reauthorization Act of 2024, the original bill to reauthorize the PRV Program last Congress.

In late December 2024, a bipartisan healthcare policy package, including the Give Kids a Chance Act, was released and set to be included in the end-of-year government funding extension. Due to forces unrelated to the healthcare policy package or the rare disease community, most health provisions, including the PRV Program, Accelerating Kids Access to Care Act, and cancer research funding, were excluded from the final bill. Unfortunately, the Pediatric Rare Disease Priority Review Voucher Program expired on December 20, 2024.

We're not done fighting for the reauthorization of the PRV Program. We will continue to update the community on opportunities to make it a reality during this Congress.

Support the fight to reauthorize the PRV Program by sending a message to your members of Congress. You can use the template text as the basis for your message and customize it with your rare disease story. *Do you have five more minutes after sending your message?* Use the Action Center to find the

phone numbers for your members of Congress and place a call to let them know you want them to ensure the PRV Program is reauthorized right away.

TEMPLATE MESSAGE TO CONGRESS TEXT

(advocates are encouraged to customize the template text with details on how pediatric rare diseases have affected their lives)

Subject Line: Please Ensure the Rare Pediatric Disease PRV Program is Reauthorized Now

Template Text for House-Targeted Messages

As your constituent and someone personally affected by a rare disease, I urge you to act early in the 119th Congress to reauthorize the Rare Pediatric Disease Priority Review Voucher (PRV) Program by passing the Give Kids a Chance Act of 2025 (H.R. 1262/S. 932). This vital program, which comes at no cost to taxpayers, has been a proven driver of innovation in treating diseases that disproportionately affect children.

Despite passing the House with strong bipartisan support and inclusion in last year's end-of-year healthcare policy package, the PRV Program expired on December 20, 2024, leaving one less resource to help bring treatments to a rare disease community in which only five percent of diseases have an FDA-approved treatment.

Reauthorizing this program is essential. Seventy percent of rare diseases start in childhood. Developing treatments for rare pediatric diseases involves unique challenges, including very small populations, complexities in conducting clinical trials in children, the nature of many pediatric genetic diseases, and delays in diagnosis. Without the PRV Program, an already limited pipeline for rare pediatric treatments becomes even weaker.

Congress has an opportunity to restore this vital program and support rare disease families facing life-threatening conditions throughout the US. I urge you to champion its reauthorization and ensure that children with rare diseases are not left without hope.

I am grateful for your leadership and ongoing commitment to the health and well-being of the 30 million Americans with a rare disease.

Template Text for Senate-Targeted Messages

As your constituent and someone personally affected by a rare disease, I urge you to act early in the 119th Congress to reauthorize the Rare Pediatric Disease Priority Review Voucher (PRV) Program. The Give Kids a Chance Act of 2025 (S. 932) has been reintroduced. This vital program, which comes at no cost to taxpayers, has been a proven driver of innovation in treating diseases that disproportionately affect children.

Despite passing the House with strong bipartisan support and inclusion in last year's end-of-year healthcare policy package, the PRV Program expired on December 20, 2024, leaving one less resource to

help bring treatments to a rare disease community in which only five percent of diseases have an FDA-approved treatment.

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