



Biotechnology Innovation Organization
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March 7, 2025

The Honorable Mike Johnson
Speaker of the House
U.S. House of Representatives
Washington, DC 20515

The Honorable John Thune
Majority Leader
U.S. Senate
Washington, DC 20510

The Honorable Hakeem Jeffries
Democratic Leader
U.S. House of Representatives
Washington, DC 20515

The Honorable Charles Schumer
Democratic Leader
U.S. Senate
Washington, DC 20510

Dear Speaker Johnson, Democratic Leader Jeffries, Majority Leader Thune and Democratic Leader Schumer:

One thing that we can all agree on is the need to give our children a fighting chance so they can lead long and productive lives. **That is why it is critical to pass the bipartisan *Give Kids a Chance Act* and ensure the **Pediatric Priority Review Voucher Program (PPRV)** is reauthorized.** This program will provide greater certainty to small biotech companies, but more importantly, hope to children and families living with rare diseases.

Today, I write to you as the President and CEO of the Biotechnology Innovation Organization (BIO), and as the father of two children with Pompe disease – a severe and often fatal neuromuscular disorder. When I learned of my children’s diagnosis in 1998, I was heartbroken, but also resolute. Through the relentless pursuit of medical research, funding, and support I helped to develop a treatment that saved their lives, and today they are thriving young adults. My family was fortunate – but today there are thousands of children living with rare diseases who are still waiting for their breakthrough. Passing the Give Kids a Chance Act and reauthorizing the PPRV program will help ensure no parent ever has to hear the words “there’s nothing we can do.”

BIO is the world’s largest advocacy organization, representing approximately 1,000 members with a central mission – supporting the policies, regulations, and ecosystem that increase access to innovation and make our industry’s discoveries possible. The majority of BIO’s members are research-intensive, biotechnology companies working on cutting-edge medical breakthroughs to improve the health of patients and families.

The PPRV was created in 2012 to solve a problem in rare drug development. While treatments for rare pediatric conditions exist, options remain limited due to the high cost of development and utilization by a smaller section of the patient population. This program has proven successful, which is why it has been reauthorized with bipartisan support three times. The PPRV has become an integral part of the biotech ecosystem and supports virtuous cycle of innovation.

There are some issues facing Congress where restraint may make sense. After all, the decisions rendered by the U.S. Senate and House of Representatives can be monumental. But this legislation does not need further review. In its simplest form, the *Give Kids a Chance Act* is a life-saving measure for children and families who simply cannot afford to wait any longer.



BIO urges you to pass the *Give Kids a Chance Act* – to provide certainty to small biotechs but, more importantly, greater hope to children and their families everywhere.

Sincerely,

A handwritten signature in black ink that reads "J. F. Crowley". The signature is fluid and cursive, with the first letters of each name being capitalized and prominent.

John F. Crowley
President & CEO