

THE NEW ENGLAND COUNCIL

May 9, 2024

Dear New England Delegation:

I write to you today in support of S. 3131 and H.R. 5539, the Optimizing Research Progress Hope and New (ORPHAN) Cures Act. As you may know, the New England Council is a non-partisan alliance of businesses, academic and health institutions, and public and private organizations throughout New England. Our mission is to promote economic growth and a high quality of life in the region, and it is with that background that I urge you to consider the ORPHAN Cures Act.

The ORPHAN Cures Act has bipartisan support in both the House and Senate and is aimed at boosting rare disease drug development to ensure that patients have access to innovative therapies. Orphan drugs are drugs that target rare diseases, which are defined as diseases that affect fewer than 200,000 people in the United States. Currently, fewer than 5 percent of rare diseases have an FDA-approved treatment. Due to the nature of orphan drugs benefiting small patient populations, incentives to invest in these treatments are limited.

Currently, under the Inflation Reduction Act, orphan drugs are exempt from government price negotiations, but only if the drugs are approved for a single indication. Ultimately, this provision removes the incentive for drug manufacturers to test whether an orphan product can treat other conditions. Of the more than 280 orphan drugs approved since 2003, nearly a quarter were later approved to treat additional diseases.

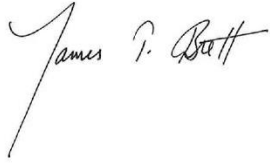
The ORPHAN Cures Act would ensure that the Medicare Drug Price Negotiation Program's provide an exemption for orphan drugs from negotiation eligibility so long as the product is used exclusively for rare diseases.

In fact, on April 23, 2024, the New England Council hosted a program focused on challenges and opportunities for continued innovation to treat rare diseases. The ORPHAN Cures Act was mentioned repeatedly as a key tool in developing and treating rare diseases, and it is with that in mind that the New England Council urges you to support this important legislation. If you have any questions, please feel free to contact Sean Malone on my staff at smalone@newenglandcouncil.com.

Sincerely,

The New England Council

98 North Washington Street, Suite 301 • Boston, Massachusetts 02114 • (617) 723-4009
1411 K Street, NW, Suite 700 • Washington, DC 20005 • (202) 547-0048
www.newenglandcouncil.com

A handwritten signature in black ink that reads "James T. Brett". The signature is written in a cursive style with a large, stylized initial "J".

James T. Brett
President & CEO

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