

SAVE THE ORPHAN DRUG TAX CREDIT!

Congress, we're relying on you! #SaveOrphanDrugs

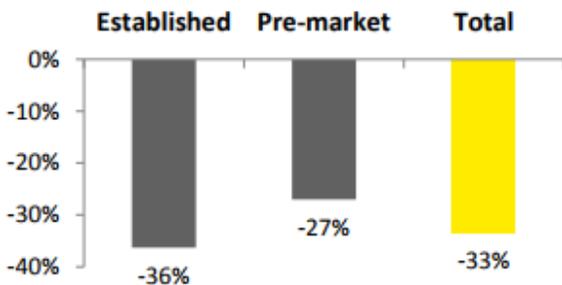
What is the Orphan Drug Tax Credit (ODTC)? The Orphan Drug Tax Credit allows drug manufacturers to claim a tax credit of 50 percent of the qualified costs of clinical research and drug testing of orphan drugs (drugs for diseases affecting 200,000 Americans or fewer).

What is the ODTC's History? The ODTC is part of a package of provisions enacted in 1983 in the Orphan Drug Act (ODA) that provides incentives for drug companies to develop products for rare diseases.

Has the ODTC been successful? Yes! In the decade before the ODA, only 10 medicines were developed by industry for rare diseases. Since 1983, however, more than 3,500 potential treatments have been designated as an orphan drug and more than 500 orphan therapies have been approved by the Food and Drug Administration (FDA). This is a direct result of the incentives provided by the ODA, including the tax credit.

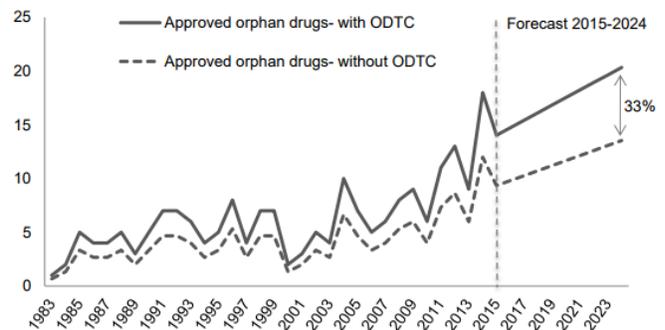
What would happen if the Orphan Drug Tax Credit is repealed?

Estimated Decline in Investment in Orphan Drugs by Type of Developer Under Potential ODTC



Source: EY analysis.

Estimated Impact of Potential ODTC Repeal on New Orphan Drugs



Note: Projection beyond 2014 is based on the annual average change in orphan drug NME and new BLA approvals from 2004 to 2014 with and without the ODTC.

Source: Drug Approval Reports, Food and Drug Administration, various years; EY analysis.

What does the House bill do?

The House-passed *Tax Cuts and Jobs Act* **entirely repeals the Orphan Drug Tax Credit**

What does the Senate bill do?

The Senate Finance Committee-passed *Tax Cuts and Jobs Act* **lowers the credit's value from 50 percent of qualified clinical testing expenses to 27.5 percent.**

Who will this impact?

Liz, Pennsylvania

Liz, who was born with a rare mitochondrial disease, is one of the rare disease community's most passionate advocates. Liz spends her time advocating for all patients with rare diseases and is routinely on Capitol Hill. There is no treatment or cure for her condition.



Annabelle, Virginia

Annabelle was born with an incredibly rare disease known as MPS IV A. Now that the very first orphan drug has been approved for her condition, she can play on the playground without experiencing pain.



Madilyn, Alabama

Madilyn was born with an incredibly rare disease known as CCHS. Madilyn's body essentially "forgets to breathe," requiring extensive monitoring and care. There is no treatment or cure for her condition.

