



December 12, 2017

The Honorable Kevin Brady
1011 Longworth House Office Building
Washington, DC 20515

The Honorable Orrin Hatch
104 Hart Office Building
Washington, DC 20510

Dear Representative Brady, Senator Hatch, and Conferees:

On behalf of the Epilepsy Foundation, I urge you to ensure continuation of the Orphan Drug Tax Credit (ODTC) in H.R. 1 – the Tax Cuts and Jobs Act. The Orphan Drug Tax Credit is one of the only tax credits that saves lives. With 95 percent of individuals who live with a rare disease still waiting for a treatment, including many with rare forms of epilepsy, I hope you will work to maintain this critical incentive for orphan drug development.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the at least 3.4 million Americans with epilepsy and seizures. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime. More than one third of people living with epilepsy are not able to reach seizure control with current FDA-approved therapies. Many have rare forms of epilepsy that would benefit from companies investing in the rare disease space.

The ODTC has been extremely successful in incentivizing innovation in the rare disease space. The 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). It was 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.

In the decade before the Orphan Drug Act, only ten 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 FDA. This is a direct result of the incentives provided by the ODA, including the tax credit.

Of the approximately 7,000 diseases considered rare in the U.S., only a few hundred have FDA-approved treatments. This leaves millions of Americans with diseases that currently have no treatment or cure. The Orphan Drug Tax Credit gives hope to individuals with rare diseases without a treatment that one day they too will have a treatment, or even cure. Please

support this important policy priority for millions of Americans, including the epilepsy community. If you have any questions or concerns, please contact Angela Ostrom, Chief Legal Officer & Vice President Public Policy at aostrom@efa.org or 301-918-3766.

Sincerely,



Philip M. Gattone, M.Ed.
President & CEO
Epilepsy Foundation

cc:

- Rep. Bishop
- Rep. Black
- Rep. Castor
- Rep. Doggett
- Rep. Grijalva
- Rep. Levin
- Rep. Neal
- Rep. Noem
- Rep. Nunes
- Rep. Roskam
- Rep. Shimkus
- Rep. Walden
- Rep. Young

- Sen. Cantwell
- Sen. Carper
- Sen. Cornyn
- Sen. Enzi
- Sen. Menendez
- Sen. Murkowski
- Sen. Murray
- Sen. Portman
- Sen. Sanders
- Sen. Scott
- Sen. Stabenow
- Sen. Thune
- Sen. Toomey
- Sen. Wyden