



Highlights from the Hill

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We encourage you to invite others to join our [Speak Up, Speak Out!](#) advocacy network. Members receive the monthly *Highlights from the Hill* newsletter and alerts about opportunities to advocate for the epilepsy community throughout the year. Growing our advocacy network is critical to achieving our public policy goals as we move through busy state and federal legislative sessions. Make a difference today by sharing our Speak Up, Speak Out! Network on [Facebook](#) and [Twitter](#).

National Advocacy

Over 100 Days Since Children's Health Insurance Program Funding Expired

The Children's Health Insurance Program (CHIP) provides health insurance for 8.9 million children through state-run, federally-funded programs. For children in working families that earn too much to qualify for Medicaid, but too little to purchase private health insurance, or children living with complex chronic conditions like rare epilepsies, CHIP is a lifeline to medical care.

Federal funding for CHIP expired on September 30, 2017 and needs to be reauthorized soon because the delay is having an impact on the program. Thousands of families are receiving notices informing them of when their children's benefits will end and some states have stopped enrolling children. Despite longstanding bipartisan support for CHIP, Congressional leaders have not been able to reach an agreement on how to pay for the cost of the program.

The week of January 8, 2018 marked 100 days since Congress allowed long-term funding for the Children's Health Insurance Program (CHIP) to expire. On December 21, 2017, Congress passed a short-term continuing resolution (CR) that funds the government until January 19, 2018. The CR included temporary funding for CHIP through March 31, 2018. This was welcome news for the nearly 9 million children who depend on CHIP, however we still need a permanent fix. The short-term funding is not sufficient. **[The Center for Medicare & Medicaid Services \(CMS\) has said that the funding that is supposed to last until March may begin to run out for some states by the January 19th deadline.](#)** We join Governors, state leaders, and children's health advocates in urging Congress to reauthorize CHIP funding for multiple years.

The nonpartisan Congressional Budget Office (CBO) has released new estimates for long-term funding of CHIP. **[CBO found that a five-year extension would cost about \\$800 million over a ten-year period, which is \\$7.4 billion less than the original estimate of \\$8.2 billion. Additionally, CBO estimated that extending funding for CHIP for 10 years, instead of five, would decrease the deficit by \\$6 billion over a ten-year period.](#)**

On January 17, 2018, the House Republican leaders released the text of a new CR that would fund the government through February 16, 2018 and would also extend CHIP for 6 years. The Epilepsy Foundation is closely monitoring the situation and we will continue to advocate for the reauthorization of CHIP for multiple years.

[ACT NOW: Tell Congress to Reauthorize CHIP!](#)

Read more about CHIP and follow our efforts at **advocacy.epilepsy.com/CHIP**.

Tax Reform Bill Signed into Law

On December 22, 2017, President Trump signed into law the *Tax Cuts and Jobs Act*, H.R. 1, legislation which reforms the U.S. tax code and impacts certain aspects of access to health care and medical innovation.

One of the proposals contained within the Senate and House tax bills was the reduction or elimination of the Orphan Drug Tax Credit (ODTC), an important incentive for companies to develop therapies for individuals with rare diseases. 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 this space. The existing tax credit allowed drug manufacturers to claim a tax credit of 50 percent of the qualified cost of clinical research and drug testing of orphan drugs (drugs for diseases affecting 200,000 Americans or fewer). In the final bill signed into law the tax credit was reduced from 50 percent to 25 percent. The Epilepsy Foundation was opposed to the weakening of this important tax

credit, but is grateful for Senate leadership in preserving a partial credit to foster investment and innovation in therapies for rare conditions.

Additionally, the tax reform legislation repealed the Affordable Care Act's individual mandate. While the actual effect of the repeal of the individual mandate is unknown at this time, it is projected to have an impact on uninsured rates and insurance premiums. Without the individual mandate, the number of people with health insurance will most likely decrease and insurance premiums will increase.

Read more about tax reform, the Orphan Drug Tax Credit, and the Epilepsy Foundation's engagement at advocacy.epilepsy.com/2017taxreform.

Tell Congress to Protect State Medical Cannabis Programs

An amendment to prevent the Department of Justice from spending federally appropriated funds to interfere with state medical cannabis programs has been included in previous years' appropriations bills, and it is crucial that this provision is included in the final funding package again this year. Congress passed another short-term continuing resolution to fund the government through January 19, 2018, but they still must pass a full funding bill. The Epilepsy Foundation remains committed to advocating for this important provision to be part of the final funding bill.

This provision is a priority for people living with uncontrolled seizures who have reported beneficial effects and reduced seizure activity when using medical cannabis, especially strains rich in CBD. Uncontrolled seizures can lead to disability, injury, and even death. Medical use of cannabis and/or CBD is legal per state law in 45 states and the District of Columbia.

The Epilepsy Foundation is committed to supporting physician-directed care, and to exploring and advocating for all potential treatment options for epilepsy, including medical cannabis and CBD. If a patient and their health care providers feel that the potential benefits of medical cannabis and CBD outweigh the risks, then families need to have that legal option. We continue to support lifting federal barriers to research on cannabis and CBD and support access to these potential therapies through state-regulated programs, in consultation with the treating physician, for individuals living with intractable epilepsy and when other treatment options have failed.

[Urge Congress to Protect State Access to Medical Cannabis Laws](#)

Read more about medical cannabis advocacy at advocacy.epilepsy.com/medical-cannabis.

STATE ADVOCACY

Pennsylvania Governor Signs Bill to Improve Access to Some Epilepsy Medications

On December 22, 2017, Governor Wolf signed Senate Bill 728 into law, exempting Schedule V epilepsy drugs from the state's prescription drug monitoring program (PDMP). Senator Yaw and Representative DiGirolamo championed the bill. Elizabeth Beil, President & CEO of Epilepsy Foundation Eastern Pennsylvania, was quoted in Senator Yaw's press release about the signing of this legislation, which you can read [here](#).

For several years the Epilepsy Foundation has advocated with Pennsylvania legislators to remove Schedule V epilepsy medications from the state's PDMP because monitoring requirements can delay access to epilepsy treatments, putting individuals at risk for breakthrough seizures and related complications. PDMPs are intended to curb prescription drug abuse by carefully monitoring the prescribing and dispensing of Scheduled medications, but people with epilepsy are not abusing epilepsy medications. Exempting Schedule V non-opioid medications is a simple way to ensure timely access to physician-directed care while still addressing prescription drug abuse via the monitoring program.

Thank you to everyone who has advocated for passage of this exemption over the years. We hope to pursue similar legislation in other states in the 2018 state legislative session. Follow this issue across all of the states and learn more at advocacy.epilepsy.com/PDMP.

Legislation to Improve Access to Care and Enhance Consumer Protections Introduced in Various States

As the 2018 state legislative sessions begin across the United States, the Epilepsy Foundation remains committed to protecting access to physician-directed care for people living with epilepsy and to opposing step therapy requirements, medication switching, substitution, and other barriers to quality care.

For the majority of people living with epilepsy, medications are the most common and cost-effective treatment for controlling and/or reducing seizures. Epilepsy medications are not interchangeable, and treatment of epilepsy is highly individualized - there is no "one size fits all" treatment option. People living with epilepsy who have their medications switched, or who experience a delay in accessing their medication are at a high risk for developing breakthrough seizures and related complications, including death.

In Washington, Colorado, New Jersey, Florida and Iowa, bills have been introduced that would prevent insurers from changing the medications they cover in the middle of the plan year. The Epilepsy Foundation is a strong supporter of these bills. If prescription drug benefits are changed mid-year, beneficiaries can be left with higher out-of-pocket costs, or with no coverage at all for a necessary therapy. People with epilepsy choose their insurance based on the coverage details provided at the time of enrollment, and can be seriously harmed by unilateral mid-year changes in prescription drug coverage. People who buy insurance cannot change the terms of their plans mid-year; insurance companies should not be able to do so either.

Legislation designed to reduce the burden of step therapy requirements has been introduced in Virginia, Minnesota, New Mexico, Florida, and Washington. Step therapy, or fail first, is a process that requires individuals who have been prescribed certain medications to

try and fail one or more medications preferred by the insurer before receiving the medication their physician prescribed. The Epilepsy Foundation opposes onerous step therapy requirements and similar policies intended to restrict access to physician-directed care that unnecessarily prolong ineffective treatment, and prevent individuals from immediately starting the treatment their providers think is best.

As legislatures get up and running in all states, the Epilepsy Foundation will be closely monitoring new legislation that pertains to our policy priorities. Stay up to date with the legislation in your state by going to advocacy.epilepsy.com/efa/states .

Read more about mid-year formulary changes at advocacy.epilepsy.com/formulary-changes and learn more about our step therapy advocacy efforts at advocacy.epilepsy.com/efa/StepTherapy.

Update Your Contact Information for Speak Up, Speak Out Advocacy Network

Most state legislatures are in session! We want to make sure you are well informed about what is happening right in your backyard and that you don't miss an opportunity to share your voice with state and local policymakers.

To ensure you don't miss out, please take a minute to update your contact information, including your home address, so that we can send targeted alerts based on your state and congressional district. Please do so by completing the form [here](#) - which is used only for our Speak Up, Speak Out advocacy network.

Email us at TSU@efa.org

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