



# Highlights from the Hill

December 2017

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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](#).

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### National Advocacy

**[Protecting Patient Access to Emergency Medications Act of 2017 Signed into Law](#)**

The Protecting Patient Access to Emergency Medications Act of 2017, H.R. 304, was signed into law by President Trump on November 17, 2017. The Epilepsy Foundation supported this bill since it was first introduced in the last Congress.

The bill clarifies that emergency medical services (EMS) agencies can continue to administer controlled medications when responding to an emergency, including seizures. There is a demonstrated clinical need for administering controlled substances to treat active seizures during an emergency and delaying immediate treatment by first responders with a readily available emergency medication can be life-threatening. Prolonged, cluster, or status seizures may cause serious injury and even death.

### **Update: Children's Health Insurance Program Reauthorization**

The Children's Health Insurance Program (CHIP) provides health insurance for 8.9 million children through Medicaid and separate CHIP programs administered by the states individually. For children in working families that earn too much to qualify for Medicaid, but too little to purchase private health insurance, CHIP is a lifeline to medical care. The program's current federal funding expired on September 30, 2017 and needs to be reauthorized immediately as the delay is already having an impact on the program.

Temporary CHIP funding was included in the short-term continuing resolution (CR), H.J. Res 123, that funds the government until December 22, 2017 and was signed by the President on December 8, 2017. The provision allows states who are running out of CHIP funds to access additional funding as Congress works to reauthorize the program. While this temporary fix was welcome, it is not a substitute for a full, long-term reauthorization of the funding for CHIP.

The House has passed a CHIP bill while the Senate still need to consider the bill and pass it before it will be sent to the president for enactment. The Epilepsy Foundation will continue to advocate for the reauthorization of CHIP. [\*\*ACT NOW: Tell the Senate to reauthorize CHIP!\*\*](#)

Read more about CHIP and follow our efforts at [advocacy.epilepsy.com/CHIP](http://advocacy.epilepsy.com/CHIP).

### **Tell Congress to Protect State Medical Cannabis Access Programs**



A provision to prevent the Department of Justice from spending funds to interfere with state medical cannabis programs has been included in previous years' appropriations bills, and it is crucial that this amendment is included in the final funding package again this year. Congress just passed a short-term continuing resolution, H.J. Res 123, to fund the government through December 22, 2017 but they still must pass a full funding bill. The Epilepsy Foundation is 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, for individuals living with intractable epilepsy and when other treatment options have failed, in consultation with the treating physician.

### **[Act Now! Urge Congress to Protect State Access to Medical Cannabis Laws](#)**

Read more about medical cannabis advocacy at [advocacy.epilepsy.com/medical-cannabis](https://advocacy.epilepsy.com/medical-cannabis).

*Image: Advocates from Iowa met with Senator Grassley and other members of Congress on November 30 to advocate for medical cannabis access and research. From left, Beth Collins with Americans for Safe Access; Senator Grassley, Kim Novy and Sally Gaer, advocates with Epilepsy Foundation Iowa; and Epilepsy Foundation national staff, Beatriz Duque Long.*

### **Epilepsy Foundation Supports CDC Appropriations Ask for FY 2018**

On December 4, 2017, the Epilepsy Foundation signed letters sent to the [House](#) and [Senate](#), with more than 150 state and national organizations in support of at least a \$7.8 billion funding level for the Centers for Disease Control and Prevention (CDC) in Fiscal Year 2018.

The Epilepsy Foundation believes epilepsy should be a federal public health priority and supports investments in public health programs that help build safer communities, end stigma associated with epilepsy, educate community leaders, and build awareness that benefits everyone with epilepsy and other chronic health conditions and disabilities. We urge Congress to continue to invest in critical epilepsy public health programs at the CDC to ensure the safety and health of people with epilepsy.

Read more about federal funding for epilepsy programs at [advocacy.epilepsy.com/federal-funding-for-epilepsy](https://advocacy.epilepsy.com/federal-funding-for-epilepsy).

## Impact of Tax Reform on the Epilepsy Community

On November 16, 2017, the House passed the *Tax Cuts and Jobs Act*, H.R. 1, by a vote of 227-205. Then, on December 2, the Senate passed their version of a tax reform bill, by a vote of 51-49. Now the chambers will resolve the differences in the bills in a conference before finalizing a bill to send to the President for his signature.

The Epilepsy Foundation has been closely monitoring the tax reform proposals being considered by Congress. Our primary concern is the negative impact of the projected deficit created by the proposed tax cuts on the federally funded programs and services our community relies on, like Medicare, Medicaid, and the ACA. [The Congressional Budget Office estimates that the House bill would add nearly \\$1.5 trillion to the deficit over the next decade.](#) This could mean mandatory cuts to Medicare and a renewed push for radically restructuring the way the federal government supports Medicaid programs in the states.

We have not engaged in support or opposition to many individual provisions being considered - like the medical deduction or the doubling of the standard deduction - because in the end, our overarching concern remains the future program cuts that would be triggered by the projected deficit. One third of people living with epilepsy rely on Medicaid, while a sixth rely on Medicare, and many more rely on programs and services like the Epilepsy Program at the Centers for Disease Control and Prevention (CDC) and the research taking place at the National Institutes of Health (NIH). We have joined many patient advocacy organizations in expressing concern with the repeal of the individual mandate included in the Senate tax reform bill because it would further destabilize the individual insurance market (ACA Marketplace). The Congressional Budget Office estimates that 13 million people would become uninsured if the mandate is repealed, which would result in higher premiums for people who remain in the individual market, including people living with epilepsy and other pre-existing conditions.

Read more about tax reform and the Epilepsy Foundation's engagement at [advocacy.epilepsy.com/2017taxreform](http://advocacy.epilepsy.com/2017taxreform).

## Ask Congress to Preserve the Orphan Drug Tax Credit

As the House and Senate finalize the tax reform package, we are also particularly concerned about continuation of the Orphan Drug Tax Credit. The Epilepsy Foundation is opposed to repealing or weakening this important tax credit, which has been extremely successful in incentivizing innovation in the rare disease space. 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 Orphan Drug Tax Credit gives hope to the nearly 95 percent of individuals with rare diseases without a treatment that one day they too will have a treatment, or even cure.

You can take action now! [Call Congress Today: Tell Members to Reject Tax Plans that Would Increase Deficits that Jeopardize Spending on Health Programs](#) and [Tell Congress: Preserve the Orphan Drug Tax Credit.](#)

## **Epilepsy Foundation Advocates for Brain Surgery**

On December 12, 2017, the Epilepsy Foundation was featured in a [CNN article](#) supporting a teenager who has been denied coverage for a laser ablation surgery, an FDA-approved procedure that has shown to be effective for individuals in the epilepsy community. Thousands of Americans with seizure disorders often face similar obstacles from insurers. The Epilepsy Foundation advocates access to all effective treatments and therapies so people living with epilepsy can live to their fullest potential. We are currently taking steps to ensure health insurance companies understand the critical role surgery can play in seizure control.

Have you had brain surgery to control your seizures? Share with us your story [here](#).

Follow the Epilepsy Foundation's advocacy for access to devices and surgery at [advocacy.epilepsy.com/efa/device\\_surgery-access](http://advocacy.epilepsy.com/efa/device_surgery-access).

## **Epilepsy Foundation Submits Comments to Proposed ACA Rule**

On November 27, 2017, the Epilepsy Foundation [submitted comments](#) to the U.S. Department of Health and Human Services (HHS) on the proposed rule, Notice of Benefit and Payment Parameters for 2019, which would allow states to scale back essential health benefits insurers must offer to their beneficiaries in the ACA Marketplaces. Also, as leaders of the I Am Essential coalition, the Epilepsy Foundation and many of our local chapters and affiliates, joined a [comment letter](#) to HHS that included 138 patient and community organizations.

The Epilepsy Foundation applauds HHS for maintaining some critical patient protections under the ACA. However, we have concerns about the proposed changes to how states can select their required essential health benefits for plans. The new proposal would likely lead to less generous coverage and an increase in out-of-pocket costs, especially for people with chronic conditions like epilepsy.

Follow our ACA advocacy efforts at [advocacy.epilepsy.com/ACA](http://advocacy.epilepsy.com/ACA).

## **ACA Enrollment Ends December 15, 2017**

Enrollment for the 2018 Health Insurance Marketplace began on November 1, 2017. The last day to enroll in an individual plan for coverage starting in January 2018 is December 15, 2017. [There are five different ways to enroll and many different plan options](#). Please visit [HealthCare.gov](http://HealthCare.gov) to learn more and if you have any questions you can call the 24-hour Marketplace Call Center at 1-800-318-2596.

For a general overview of enrollment visit [advocacy.epilepsy.com/ACA/GettingStarted](http://advocacy.epilepsy.com/ACA/GettingStarted).

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## **STATE ADVOCACY**

## **Pennsylvania Legislature Passes Bill to Ease Access Burdens to Epilepsy Medication**

On December 13, 2017, the Pennsylvania legislature voted out a bill that would remove Schedule V epilepsy medications from the state's prescription drug monitoring program (PDMP). The House passed Senate Bill 728, which has previously passed the Senate, and the bill now heads to the Governor. **[If you live in Pennsylvania, write now to encourage Governor Wolf to sign this bill into law!](#)**

For several years the Epilepsy Foundation has advocated with Pennsylvania legislators to remove Schedule V epilepsy medications from the state's PDMP. Inclusion of Schedule V drugs 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](http://advocacy.epilepsy.com/PDMP)**.

## **2018 State Legislative Sessions**

The end of the year is fast approaching! The majority of state legislative sessions will begin in January 2018. The Epilepsy Foundation is ready to lead advocacy efforts **to ensure access to physician-directed care** and in support of our **[policy priorities](#)**.

To review 2017 advocacy efforts in your state, **[we encourage you to visit your state's homepage](#)**. Check back in 2018 for updates.

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

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.**

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