



The Capitol Circuit

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National Advocacy

Tell Secretary Azar and Administrator Verma to Preserve Access to Anticonvulsants

In late November 2018, the Centers for Medicare and Medicaid Services (CMS) released a proposed rule aimed at lowering prescription drug costs that would weaken Medicare Part D's six protected classes - making it harder for people with epilepsy to access their anticonvulsants.

Medicare's six protected classes were designed to ensure that Medicare Part D beneficiaries living with serious conditions — like epilepsy, HIV, mental illness, cancer and organ transplants — have reliable and affordable access to life-changing and life-saving medications.

The Foundation is deeply concerned by the Administration's proposal, which would allow new formulations of existing drugs to be excluded from the formularies and would force people to go through more prior authorization and step therapy - even if they're currently stable on an anticonvulsant. In January 2019, the Foundation joined over 60 patient groups in an [ad campaign](#) to send a message to Secretary Azar and spread awareness about the importance of safeguarding the six protected classes policy.

The Foundation will be submitting comments but it's vital that the Administration also hear from people living with and affected by epilepsy. [We urge you to submit a comment to CMS to preserve the six protected classes policy and timely access to anticonvulsants.](#) The public comment period closes Friday, January 25, 2019 so take action today!

Learn more about Medicare's six protected classes at advocacy.epilepsy.com/ProtectedClasses.

116th Congress Begins

On January 3, 2019, the 116th Congress began amid a partial federal government shutdown. The Department of Health and Human Services, which contains critical funding for epilepsy research and programs through the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH), was fully funded for 2019 back in September, and is not affected by the shutdown. However, nine federal departments and various agencies remain unfunded including some that are important to the epilepsy community like the Food and Drug Administration. The Foundation continues to monitor the impact of the partial shutdown, particularly among federal workers with epilepsy. If you are experiencing difficulties in affording your medications due to the shutdown, please contact our 24/7 helpline at 1-800-332-1000.

There have been significant changes in leadership, committee leadership and committee membership in the House, as well as in the Senate. As a result of the 2018 midterm elections, the Democratic Party is now in the majority in the House of Representatives and the Republican Party maintained its majority in the Senate. Committee memberships are still being finalized in the House, however below you can view leadership positions and membership assignments for finalized committees.

Senate

- [Leadership](#)
- [Appropriations](#)
- [Finance](#)
- [Health, Education, Labor and Pensions \(HELP\)](#)

House

- [Leadership](#)

- **Appropriations**

Farm Bill Signed into Law, Legalizing Hemp and Hemp-Derived CBD

On December 20, 2018, the President signed the 2018 Farm Bill, H.R. 2, into law. Of importance and promise to the epilepsy community is that part of the farm bill legalizes hemp and hemp-derived cannabidiol (CBD) by changing the definition of hemp to include any cannabis plant or product derived from the cannabis plant that contains less than 0.3% THC by dry weight. It also amends the Controlled Substances Act to exempt hemp as a Schedule I substance. This will allow states to regulate the production and commerce of, as well as research related to CBD.

However, this does not mean that all hemp-derived products, including CBD, are medically appropriate for all people with epilepsy. As of now, Epidiolex® is the only FDA-approved CBD product to treat epilepsy and is specifically indicated for seizures associated with Lennox-Gastaut and Dravet syndromes. The Farm Bill does not change existing laws surrounding state medical cannabis programs. Individuals who purchase treatments through a medical dispensary and via a recommendation from their physician are still required to follow the regulations set forth including registration, renewal of medical cards, and other requirements decided by each state.

Now that the Farm Bill has been signed into law, **[read our FAQ about medical cannabis and cannabidiol](#)** to learn about the impact on the epilepsy community.

Learn more about medical cannabis and CBD, including a webinar about the impact of the Farm Bill at **advocacy.epilepsy.com/medical-cannabis**.

Epilepsy Foundation Joins 37 Patient Groups to Speak Out Against Ruling in *Texas v. US*

On December 14, 2018, a federal judge ruled that the entire Affordable Care Act (ACA) is unconstitutional because of the recent change in federal tax law that repealed the penalty associated with the individual mandate. The ACA remains intact, however, while the case continues through the court system — so coverage you have signed up for to receive in 2019 and coverage through Medicaid expansion is not yet affected.

The Foundation, along with 37 national patient groups, **[released a statement](#)** speaking out about the ruling in *Texas v. U.S.* We anticipate that the ruling will be appealed to the United States Court of Appeals for the Fifth Circuit.

Read more about our efforts to protect individuals with pre-existing conditions at **advocacy.epilepsy.com/ACA**.

Foundation Comments on 1332 Waiver Guidance from CMS

In 2018, the Centers for Medicare and Medicaid Services (CMS) issued a new guidance regarding Section 1332 waivers under the Affordable Care Act (ACA). Currently, these waivers give states the authority to pursue innovative strategies for providing their residents with access to comprehensive and affordable health insurance while retaining the basic protections of the ACA and maintaining budget neutrality.

In December 2018, the Foundation submitted a [comment letter](#) expressing concerns that the guidance relaxes important guardrails and requested that the guidance be withdrawn immediately. In addition to our own comment letter, the Foundation signed on to several of our coalition partner's comments.

Read all of the comment letters at advocacy.epilepsy.com/ACA.

STATE ADVOCACY

Seizure Safe School Legislation

Of the 3.4 million people living with epilepsy in the United States, there are 470,000 children living with epilepsy. For students living with epilepsy, it is important that schools are well-equipped with the tools necessary to provide a safe and enriching environment. The Foundation is working with local offices across the nation to pass Seizure Safe School legislation, which makes certain that school personnel, including nurses, teachers, and volunteers, are not only prepared but can recognize and respond appropriately and efficiently to the student experiencing a seizure. Even more importantly, the legislation safeguards physician-directed care in the school setting allowing students to access necessary and oftentimes life-saving medication. Lastly, by bringing awareness to the entire educational community, students living with epilepsy or a seizure disorder can feel safe in school, reach their full academic potential, and build meaningful friendships without fear of being stigmatized.

Kentucky was the first state in the U.S. to have enacted Seizure Safe School legislation. On April 13, 2018, Governor Bevin signed House Bill 147, also known as the Lyndsey Crunk Act, into law. The bill was named after the Epilepsy Foundation of Kentuckiana's 2016 Teens Speak Up! representative.

Since the 2019 state legislative sessions began, seizure safe school legislation has been introduced in Indiana, Oklahoma, and Texas. However, many local offices are working on introducing this legislation. Stay up-to-date on the latest seizure safe school legislative activity at advocacy.epilepsy.com/seizuresafeschools. Contact your local office to find out if they are working on this legislation or if there are ways you can help lay the groundwork.

2019 State Legislative Sessions

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



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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