



Highlights from the Hill

October 2018

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National Advocacy

Epilepsy Foundation Signs on to Amicus Brief in Legal Challenge to Short-Term Health Insurance Rule

On October 8, 2018, The Epilepsy Foundation joined 11 other national patient groups in filing [an amicus curiae \(or friend-of-the-court\) brief](#) in support of the U.S. District Court case, *Association for Community Affiliated Plans v. United States*, challenging the recently finalized federal rule on short-term health insurance plans. The suit was originally filed by the Association for Community Affiliated Plans, National Alliance on Mental Illness, Mental Health America, American Psychiatric Association, AIDS United, National Partnership for Women & Families, and Little Lobbyists on September 14, 2018.

Short-term health insurance plans currently exist to help individuals navigate insurance coverage gaps. Additionally, these plans can charge lower premiums since they do not need to comply with critical consumer protections created by the Affordable Care Act (ACA). Issuers of these plans, in turn, can discriminate against those who have a pre-existing condition, charge higher premiums, and impose limits on services.

The finalized rule would allow the expansion of short-term plans from three to almost 12 months, with the ability to renew. The brief argues that the expansion of these plans will weaken protections for individuals with pre-existing conditions and destabilize the insurance marketplace by siphoning younger, healthier individuals out of the market, leading to increased – potentially unaffordable – premium rates for individuals living with chronic conditions like epilepsy. People with pre-existing conditions are at risk of being underinsured or losing coverage altogether if premiums become too high. Short-term health plans are not a substitute for comprehensive, affordable health care.

Due to the overwhelming risk to people with pre-existing conditions and the insurance market, the amicus brief asks the court to issue a preliminary injunction stopping the rule and preserving current limits on short-term plans. A hearing has been scheduled for October 26, 2018 and the Epilepsy Foundation will continue to monitor this court case.

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

Drug Enforcement Administration Reschedules Epidiolex®

On September 27, 2018, the Drug Enforcement Administration (DEA) rescheduled Epidiolex® as a Schedule V substance, which is in line with the Food and Drug Administration (FDA)'s recommendation and is a big win for the epilepsy community. Schedule V drugs, substances, or chemicals are defined as drugs with lower potential for abuse than Schedule IV and consist of limited quantities of certain narcotics which are known to cause dependency. This is the lowest tier of the drug schedule. Other medicines such as certain cough syrups or antidiarrheals are also Schedule V. Schedule V medications to treat epilepsy include pregabalin (Lyrica®), lacosimide (Vimpat®), and brivaracetam (Briviact®).

Now that Epidiolex® is both FDA-approved and scheduled by the DEA, it should be ready for distribution on the market in by the end of the year. However, the DEA's determination does not override state-controlled substance laws. If a state considers cannabis a Schedule I substance under its laws, Epidiolex® cannot be prescribed until it is rescheduled by the state. The Epilepsy Foundation is actively working with legislators and regulators in these states to secure access to this potential treatment option.

[Read FAQs about FDA-approved therapies derived from CBD here.](#) The FAQ will be updated periodically so make sure to check out the link below from time to time.

Read more about our advocacy efforts on FDA-approved therapies derived from CBD at advocacy.epilepsy.com/statefdapathway.

Health Spending Package Signed into Law

In late September, Congress passed, and the President signed H.R. 6157, the fiscal year 2019 spending bill that encompasses appropriations for the Departments of Defense and Labor, Health and Human Services (HHS) and Education. This was the first time in a decade that the Pentagon was funded on time and the first time 22 years since appropriations for the Departments of Labor, HHS and Education were enacted before the September 30th deadline.

The budgets for the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) fall under HHS. Overall, the NIH received a \$2 billion increase and the CDC received a \$126 million increase from last year. The epilepsy programs at the CDC received \$8.5 million while the Special Projects of Regional and National Significance (SPRANS) received a set-aside of \$3.6 million for epilepsy programs. The CDC received \$5 million to establish the National Neurological Conditions Surveillance System, which will provide better information like incidence and prevalence on neurological conditions including epilepsy.

We thank all the grassroots advocates who took action and reached out to their members of Congress to advocate for this federal funding. We urge you to send one final thank you to Congress for passing this important part of the budget in a timely manner and for supporting epilepsy research and programs.

Take Action: Thank Congress for Supporting Epilepsy Research and Programs!

Learn more about federal funding for epilepsy programs and research at advocacy.epilepsy.com/federal-funding-for-epilepsy.

President Signs Legislation Banning Pharmacy Gag Clauses into Law

On October 10, 2018, the President signed legislation, S. 2553 and S. 2554, into law banning pharmacy gag clauses in both commercial insurance plans and in Medicare prescription drug plans. These clauses restricted pharmacists from informing customers when they can pay less out-of-pocket for prescriptions.

The Epilepsy Foundation supported these bills and applauds Congress and the Administration's efforts to help make prescription drugs more affordable. Epilepsy medications are the most common and cost-effective treatment for controlling and/or reducing seizures, so it is imperative that prescription medications remain accessible and affordable.

Epilepsy Foundations Joins 40 Organizations in Letter to HHS Regarding Medicare Advantage Plans

On October 1, 2018, 40 patient and provider organizations, including the Epilepsy Foundation, joined together and [sent a letter](#) to Secretary Alex Azar regarding a recent announcement that Medicare will permit the use of step therapy or “fail-first” protocols for Part B drugs in Medicare Advantage plans.

The letter stresses to Secretary Azar the importance of the patient-provider relationship and the negative effects that utilization management tools, such as [prior authorization](#) and [step therapy](#), can have on access to care by limiting, changing, or delaying treatment. The Epilepsy Foundation believes that a physician and their patient are in the best position to determine whether a particular medication or treatment is appropriate given the individual’s circumstances and that bureaucratic processes should not stand in the way of expert medical care and advice.

The letter urges Secretary Azar to implement beneficiary protections, specifically an exception process in certain situations like when the treatment is expected to decrease the individual's ability either to perform daily activities, occupational responsibilities, or adhere to the treatment plan; or the individual is stable on another drug to treat his or her condition.

Learn more about our Medicare advocacy efforts at advocacy.epilepsy.com/Medicare.

Open Enrollment for Medicare and the Marketplace

People seeking to buy or change their Medicare or marketplace plan must do so during open enrollment unless a specific exception occurs like moving out of state or having a baby. Since each year, plans make changes to benefits and costs, and new plans are available, your current plan may or may not be the best plan for you in 2019. It is very important to use the open enrollment time-period to compare your coverage choices and find the plan that best meets your prescription drug needs at the lowest cost.

The annual open enrollment for Medicare prescription drug coverage (part D) and Medicare Advantage began on **October 15, 2018 and will run through December 7, 2018** for coverage beginning January 1, 2019. Visit medicare.gov or call 1-800-MEDICARE (1-800-633-4227) to learn more.

[Read the 2019 Medicare Part D Open Enrollment FAQ Brochure](#)

The open enrollment period for the Health Insurance Marketplace runs from **November 1, 2018 until December 15, 2018** for coverage beginning January 1, 2019. Learn more about your options at healthcare.gov or 1-800-318-2596 (TTY: 855-889-4325). Individuals may be eligible for premium tax credits that will help make coverage more affordable. Please note that the healthcare.gov website is scheduled to be down every Sunday during open enrollment from 12 a.m. until 12 p.m. except the last Sunday due to maintenance—so consumers should plan to enroll around those time constraints.

[Read tips about the Health Insurance Marketplace](#)



Epilepsy can affect anyone with a brain. And anyone with a brain can affect epilepsy. We exist to End Epilepsy. That means increasing awareness and changing the conversation around epilepsy, improving and saving lives through care, advocacy, research and new therapies, and education, and mobilizing everyone to take action. The Epilepsy Foundation launched the #EndEpilepsy campaign on October 1, 2018. Learn more and read Lindsey's story [here](#).

STATE ADVOCACY

Epilepsy Foundation Urges Open Access to Epilepsy Medications in Connecticut

The Epilepsy Foundation is urging the Pharmacy and Therapeutics Committee in Connecticut to maintain open access to epilepsy medications - anticonvulsants - on the state Medicaid preferred drug list. Epilepsy medications are not interchangeable, and treatment is highly individualized. We oppose formulary changes that would severely restrict access and any policies that would require multiple failures or prior authorization before non-preferred medication can be secured. Failure to have access to the appropriate medication can result in increased or breakthrough seizures, injury, accidents, additional medication and hospitalization costs, loss of earnings, and unexpected death.

Read the Connecticut Pharmacy and Therapeutics Committee letter [here](#).

Visit advocacy.epilepsy.com/states to find out what is going on in your state.

Creating a Pathway for Epidiolex® in the States

Now that Epidiolex® has been federally reclassified as a Schedule V substance by the DEA, states must take action to ensure individuals living within the state can access this new treatment option. In many states, Epidiolex® must be reclassified at the state level before it can be prescribed because cannabis remains a Schedule I substance under most state laws. The Epilepsy Foundation recently sent letters urging swift rescheduling action in Connecticut, District of Columbia, Michigan, New York, Pennsylvania, Rhode Island, and Washington.

Read the letters and stay apprised of our advocacy efforts on FDA-approved therapies derived from CBD at advocacy.epilepsy.com/statefdapathway.



Michael Finley, Epilepsy Foundation of Connecticut, had the opportunity to meet with Connecticut's Congressional delegation on September 21, 2018 to discuss policy priorities. Michael is pictured with Congresswoman Rosa DeLauro (CT-03), who is the Ranking Member on the Labor, Health and Human Services, and Education Appropriations Subcommittee.

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**](#).

Email us at [**TSU@efa.org**](mailto:TSU@efa.org)

Follow us on Twitter at [**@EpilepsyFdn**](https://twitter.com/EpilepsyFdn)

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