



# Highlights from the Hill

March 2018

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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](#).



On March 7, 2018, the Epilepsy Foundation of Iowa held an advocacy day at the state capitol in Des Moines!

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## **National Advocacy**

### **Congress Approaching Omnibus Budget Deadline**

Congressional leaders reached a budget deal back in February that paved the way for a continuing resolution to keep the government open and funded until March 23, 2018. As the deadline quickly approaches, the Epilepsy Foundation is closely watching for the omnibus spending package, a bill that would fund the government through September 30, 2018. There is a strong push from Congressional leaders to include ACA marketplace stabilization provisions in the final spending package. We will continue to advocate for initiatives and agencies important to the epilepsy community, like the Epilepsy Program at CDC, research funding at NIH, and access to quality care in programs like Medicare and Medicaid.

### **Epilepsy Foundation Monitoring Policies that Destabilize the ACA Marketplace**

The Epilepsy Foundation is closely monitoring actions taken by Congressional leaders and Administration officials as they discuss a variety of proposals that aim to stabilize the marketplace and improve affordability. Several proposals gaining traction could destabilize the individual and small employer insurance market because they chip away at key consumer protections created by the ACA and lead to higher premiums and cost-sharing for people with complex chronic health conditions like epilepsy. The repeal of the ACA's individual mandate as part of tax reform and the recently proposed rules for Short-Term Limited Duration (STLD) Plans and Association Health Plans (AHPs) could disrupt the ACA marketplace.

Our latest blog post outlines how proposed changes to the individual and small group marketplace could destabilize the individual and small group insurance market and lead to higher costs for people living with epilepsy who rely on ACA plans for their health care. Check out the blog post [here](#).

### **Epilepsy Foundation & I Am Essential Coalition Comment on Association Health Plans**

On March 6, 2018, the Epilepsy Foundation and the I Am Essential coalition submitted comments on the Department of Labor's proposed rule on Association Health Plans (AHPs). The proposal would expand the definition of an employer to allow some small businesses and self-employed individuals to join together as a large employer for the sole purpose of offering health insurance. We are concerned that under the proposed rule, AHPs would be exempt from many consumer protections created by the Affordable Care Act (ACA), such as Essential Health Benefits and limits on discriminatory practices that make it harder and more expensive for older people and individuals with complex chronic conditions to obtain health insurance as younger, healthier individuals move to AHP plans with limited benefits.

You can read the Epilepsy Foundation and I Am Essential comments, as well as group comment letters the Foundation joined, at [advocacy.epilepsy.com/ACA](http://advocacy.epilepsy.com/ACA).

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Also on March 7, 2018, the Epilepsy Foundation of Kentuckiana took over the state capitol in Frankfort with their advocacy day!



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## **STATE ADVOCACY**

### **Copay Cards and Medication Affordability**

Starting this year some insurance plans and pharmacy benefit managers (PBMs) have begun to calculate copay assistance provided by manufacturers differently, and the portion paid by manufacturers does not count towards the individual's deductible – the amount of money an individual must pay before their health plan starts fully cover health benefits. This will impact each individual differently, but it will often mean high and unanticipated costs at the pharmacy counter when an individual shows up for a refill a few months into the plan year (because they are not hitting their deductible as early as they used to with the help of manufacturers' assistance).

In Rhode Island the legislature is considering a bill, Senate Bill 2532, which would make this practice the law by preventing copay assistance provided by a manufacturer via a copay card from counting toward an individual's deductible. Copay cards and coupons and other forms of assistance help keep the price of an individual's medications at a reasonably affordable price,

which help people stay on the medications they need to maintain their quality of life and manage their complex chronic conditions.

This new practice and legislation follows on the heels of a wave of state bills that limit or prohibit copay cards and copay assistance, creating a landscape that makes it increasingly difficult for people to afford the medications they need to maintain seizure control and their quality of life. Individuals who find themselves without copay assistance and who must meet a high deductible could be forced to forego lifesaving medication due to the unaffordable price.

### **Update: Indiana's Medical Cannabis Legislation**

On March 14, 2018, the Indiana legislature passed SB 52, which would create some protections for CBD retailers and require testing for CBD products. Last spring Governor Holcomb signed legislation allowing the use of cannabidiol (CBD) as a treatment option for Indiana residents living with epilepsy and uncontrolled seizures. But retailers were not able to carry CBD products and law enforcement needed clarity on the legality of CBD use and sales. SB 52 would build on last year's bill as the state moves towards a more comprehensive medical cannabis program.

**[Tell Governor Holcomb to sign SB 52 into law and support safe access to medical cannabis in Indiana!](#)**

### **Update: Prescription Drug Monitoring Program Bill Passed in Florida**

On March 8, 2018, the Florida legislature passed House Bill 351, which will remove Schedule V epilepsy medications from the state's prescription drug monitoring program (PDMP). The bill will need to be signed by Governor Scott before taking effect.

Read more about Prescription Drug Monitoring Programs and our advocacy efforts at **[advocacy.epilepsy.com/PDMP](http://advocacy.epilepsy.com/PDMP)**.

### **Advocacy Update: Creating State Pathways for FDA-approved Therapies Derived from CBD**

The Epilepsy Foundation has brought together the epilepsy community to advocate for changes to state scheduling laws to allow therapies derived from cannabidiol (CBD) and approved by the Food and Drug Administration (FDA) to become available to people living with epilepsy in a timely manner. Bills to create a state pathway for FDA-approved therapies derived from CBD have been introduced in California, Colorado, Hawaii, New Mexico, New York, and Wyoming during the 2018 state legislative sessions.

Creating a state pathway for therapies derived from CBD and approved by FDA is a time sensitive priority for the epilepsy community because FDA is currently reviewing at least one CBD-derived therapy that shows promise for the treatment of Dravet and Lennox-Gastaut syndromes (LGS), Tuberous Sclerosis Complex (TSC) and potentially other rare epilepsies. This potential treatment option has both Orphan Drug Designation and Fast Track Designation from the FDA and we are hopeful it will be approved this year.

Follow our advocacy efforts on state scheduling for FDA-approved therapies derived from CBD at [advocacy.epilepsy.com/statefdapathway](http://advocacy.epilepsy.com/statefdapathway).

### ***Spotlight on Wyoming***

Wyoming's CBD rescheduling bill passed in the Wyoming Legislature on March 8, 2018 and was signed into law by Governor Mead on March 12, 2018!

### **Advocacy Update: Ensuring Continuity of Care During the Plan Year**

The Epilepsy Foundation has been supporting bills that would improve continuity of care by limiting insurers' ability to change formularies and medication coverage mid-year. Formulary changes that interrupt continuity of care can be extremely dangerous, leading to breakthrough seizures and related complications, including death. In the 2018 state legislative cycle, continuity of care bills have been introduced in Connecticut, Florida, Illinois, Iowa, Maine, New York, Oregon, Pennsylvania, and Washington.

Learn more at [advocacy.epilepsy.com/formulary-changes](http://advocacy.epilepsy.com/formulary-changes).

### ***Spotlight on Illinois***

Read an article featuring the Epilepsy Foundation of Greater Chicago [here](#).

Read a press release featuring Bryan Anderson, President & CEO of the Epilepsy Foundation of Greater Chicago, [here](#).



On March 1, 2018, the Epilepsy Foundation of Greater Chicago stormed the halls of the state capitol in Springfield for their advocacy day!

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### **Advocacy Update: Streamlining Step Therapy Protocols**

During the 2018 state legislative sessions, the Epilepsy Foundation has been advocating for bills that would limit step therapy requirements imposed by insurance companies on people with epilepsy and other conditions. As of March 15, 2018, step therapy reform bills have been

introduced in 12 states, including: Florida, Georgia, Kansas, Maine, Massachusetts, Minnesota, New Jersey, New Mexico, Ohio, Utah, Virginia, and Washington.

Read more about step therapy and our efforts at [advocacy.epilepsy.com/StepTherapy](http://advocacy.epilepsy.com/StepTherapy).

***Spotlight on New Mexico: Governor Martinez Signs CBD Rescheduling Bill and Step Therapy Reform Bill into Law!***

New Mexico's step therapy legislation, Senate Bill 11, was signed into law by Governor Susana Martinez on February 28, 2018. Thank Governor Martinez for signing this important legislation into law [here](#). Additionally, House Bill 139, the CBD rescheduling bill, was signed into law on March 1, 2018.

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On March 14, 2018, the Epilepsy Foundation of Minnesota advocated at the state capitol in St. Paul!



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

Almost all of the 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.**

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