



# Highlights from the Hill

February 2018

## In this Issue:

### National Advocacy

- Congressional Budget Deal Impacts Priority Epilepsy Programs like CHIP and Medicare Part D
- President Trump Releases Budget Proposal
- Children's Health Insurance Program Reauthorized for 10 Years
- Regulatory Proposals Could Undermine Stability of Individual Insurance Marketplace
- Protect the Americans with Disabilities Act: Tell Congress to Oppose H.R. 620
- State Medical Cannabis Programs Remain in Jeopardy
- Alex Azar Confirmed as Secretary of Health and Human Services (HHS)

### State Advocacy

- Creating State Pathways for FDA-approved Therapies Derived from CBD
- Ensuring Continuity of Care Between Plan Years
- Streamlining Step Therapy Protocols
- Update Your Contact Information for Speak Up, Speak Out Advocacy Network

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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Epilepsy Foundation Northwest volunteer, Conner Findley, met with Representative Laurie Jinkins during his visit to the state capitol in Olympia, Washington to testify in support of S.B. 6147. Our volunteers are sharing their story and making a difference in state capitols across the country.

### **National Advocacy**

#### **Congressional Budget Deal Impacts Priority Epilepsy Programs like CHIP and Medicare Part D**

Earlier this month Congressional leaders reached a budget deal that paved the way for a continuing resolution to keep the government open until March 23, 2018. This gives appropriations committees time to finalize budget details for federal agencies and programs for the remainder of Fiscal Year 2018. What makes this latest deal different is that Congress finally agreed on raising overall funding levels so the Senate and House appropriations committees can finalize a funding bill. 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.

The budget deal includes a wide range of provisions, from an additional four-year reauthorization for the Children's Health Insurance Program (CHIP) to funding for community health centers, to changes to the Medicare program like repealing the Independent Payment Advisory Board (IPAB) and closing the so-called donut hole a year early by 2019. Manufacturers will now pay an even larger portion of the costs of medications in the coverage gap, while insurers' portion is significantly reduced. Closing the donut hole earlier will help Medicare beneficiaries in the short term, but we are evaluating the long term impact that the shift could have on the drug benefit program overall.

#### **President Trump Releases Budget Proposal**

The President's proposed budget for Fiscal Year 2019, released on February 12, 2018, outlines proposed funding levels for agencies and programs, and well as proposals for changes to federal

initiatives. Congress – not the President – ultimately crafts the federal budget, and is now focused on a budget for the remainder of Fiscal Year 2018 before they can turn to 2019. That said, the President's proposed budget signals the Administration's priorities and can inform Congress' deliberations during the budgeting process.

### **Children's Health Insurance Program Reauthorized for 10 Years**

The Epilepsy Foundation applauds congressional action on a multi-year reauthorization of the Children's Health Insurance Program (CHIP). On January 22, 2018, Congress passed and the President signed a continuing resolution that included a six-year reauthorization for CHIP. Additionally, Congress passed another continuing resolution on February 9, 2018 that extended CHIP's funding for an additional four years, for a total of ten. CHIP provides coverage for 8.9 million American children, including 2 million children with chronic conditions like epilepsy. Long-term funding for CHIP had expired on September 30, 2017 at the end of the Fiscal Year. While CHIP enjoys longstanding bipartisan support, the program went without funding for 114 days since the end of the fiscal year and many states were scrambling to keep the program going as they ran out of federal funding.

We are incredibly grateful to the grassroots advocates who helped us make it happen. Because of you, almost 5,000 letters were sent to members of Congress urging them to reauthorize CHIP. We will continue to advocate for policies on the federal and state level that benefit the epilepsy community and we hope you will continue to take action and let your voice be heard.

#### **[Thank Congress for reauthorizing CHIP!](#)**

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

You can read our original press release [here](#).

### **Regulatory Proposals Could Undermine Stability of Individual Insurance Marketplace**

In October 2017, the President issued an executive order directing federal agencies to explore changes to association health plans and short-term limited duration plans. In response to this directive, both the Departments of Labor and Health and Human Services issued proposed rules earlier this year.

The association health plans proposed rule would expand the definition of an employer, allowing more small businesses and self-employed individuals to join together for the sole purpose of offering health insurance. These plans would not have to cover Essential Health Benefits and it is unclear how they would be regulated to ensure consumers are being treated fairly.

The short-term limited duration plans proposed rule would allow insurance companies to offer health plans that do not have to cover Essential Health Benefits, and could charge individuals with pre-existing health conditions higher rates, increase deductibles, and place strict limits on benefits. While short-term limited duration plans currently exist to help individuals navigate insurance coverage gaps, they should not become a substitute for comprehensive annual plans.

Plans with less comprehensive coverage can charge lower premiums and draw in younger, healthier individuals but this shift comes at a high cost: destabilizing the ACA marketplace. We are concerned about the impact that these proposed changes would have on people with complex chronic conditions like epilepsy who rely on ACA marketplace plans. By eroding the stability of the individual and small employer insurance market, we risk returning to the days when people with pre-existing conditions couldn't obtain health insurance, could only obtain a high-cost policy that did not cover medications and services related to their pre-existing condition, or had to rely on severely underfunded high-risk pools with waiting periods for coverage. People living with serious and complex chronic conditions likely would not be able to obtain insurance policies that meet their needs with association health plans and especially with short-term limited duration plans, and they would face higher cost-sharing and out-of-pocket costs in their ACA marketplace plans.

We will submit public comments on behalf of the Epilepsy Foundation and in partnership with other patient and community groups as we continue to advocate for access to quality care for people living with epilepsy.

Learn more about our individual and small employer market advocacy efforts at [advocacy.epilepsy.com/ACA](http://advocacy.epilepsy.com/ACA).

### **Protect the Americans with Disabilities Act: Tell Congress to Oppose H.R. 620**

On Thursday February 15, 2018, the House of Representatives passed the *ADA Education and Reform Act of 2017* (H.R. 620) by a vote of 225 to 192. The bill would weaken protections for individuals living with disabilities by making it easier for businesses to avoid complying with accessibility requirements under the Americans with Disabilities Act (ADA). The Epilepsy Foundation is very disappointed to see this bill, which is an assault on the civil rights guaranteed by the ADA, move forward to the Senate. We strongly oppose this bill, and all efforts to modify the Americans with Disabilities Act that would reduce protections for the disability community.

The ADA was narrowly crafted to balance the needs of businesses and the rights of people with disabilities. H.R. 620 would upset that balance by shifting the burden for ADA compliance from business owners to people living with disabilities and nearly eliminating the ability of people with disabilities to participate fully in their communities.

Some people with epilepsy have such severe physical limitations related to their type of seizure disorder that they need accommodations to access public facilities and businesses, which is why the Epilepsy Foundation has been a significant supporter of the ADA since its passage in 1990. The ADA resulted from bipartisan efforts to promote the rights of people with disabilities and ensure they can participate fully in all aspects of American life

Read an op-ed published February 14, 2018 in *The Hill* by Tony Coelho, former Congressman from California, one of the authors of the Americans with Disabilities Act, current Board member of the Epilepsy Foundation and fierce advocate, on the importance of the ADA and how H.R. 620 would affect the disability community [here](#).

**[Take action to protect the Americans with Disabilities Act. Urge Congress to Oppose H.R. 620!](#)**

Learn more about our efforts on the ADA at [advocacy.epilepsy.com/ADA](http://advocacy.epilepsy.com/ADA).

## **State Medical Cannabis Programs Remain in Jeopardy**

An amendment to prevent the Department of Justice from using 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 be included in the final funding package again this year. Congress passed another short-term continuing resolution to fund the government through March 23, 2018 and is now working on a funding bill for the remainder of Fiscal Year 2018. 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 enjoyed some form of legal protection 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 medical cannabis as a potential treatment option through state-regulated programs, in consultation with the treating physician, for individuals living with intractable epilepsy and when FDA-approved treatment options have failed.

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

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

### **Alex Azar Confirmed as Secretary of Health and Human Services (HHS)**

On January 24, 2018 the Senate confirmed Alex Azar as Secretary of Health and Human Services (HHS) by a vote of 55-43. The Department of Health and Human Services houses many important agencies pertaining to health services, such as the Centers for Medicare & Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), and the National Institutes of Health (NIH).

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## **STATE ADVOCACY**

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

The Epilepsy Foundation continues to bring 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. Each state has its own laws and processes for scheduling prescription medications separate from the federal system and we will continue to collaborate with affiliates and chapters to ensure timely access to FDA-approved therapies derived from CBD.

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 could be approved as soon as summer 2018.

During the 2018 state legislative session, bills to ensure timely access to FDA-approved therapies derived from CBD have been introduced in **California, Colorado, Hawaii, New Mexico, New York, and Wyoming.**

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

### **Ensuring Continuity of Care Between Plan Years**

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. Medication formulary changes that interrupt continuity of care can be extremely dangerous and lead to breakthrough seizures and related complications including death.

In the 2018 state legislative cycle bills that would improve continuity of care by limiting insurers' ability to change formularies mid-year and related continuity of care protections have been introduced (or will soon be introduced) in **Florida, Iowa, Maine, New York, Oregon, Pennsylvania, and Washington.**

#### ***Spotlight on Iowa and Washington***

Read an op-ed by Roxanne Cogil, Executive Director of the Epilepsy Foundation Iowa, on this issue [here](#).

Read an op-ed by Sharon Cupp, Executive Director of the Epilepsy Foundation Northwest, on this issue [here](#).

Read more about continuity of care and our efforts at [advocacy.epilepsy.com/formulary-changes](http://advocacy.epilepsy.com/formulary-changes).

### **Streamlining Step Therapy Protocols**

Step therapy, or "fail first," is a process used by insurance companies to require enrollees to try and fail on other medications – usually older and cheaper medications -- preferred by their insurers before receiving the medication their physician originally prescribed.

In the 2018 state legislative cycle bills that would require a streamlined appeals process with step therapy override protocols have been introduced (or will soon be introduced) in the following states: **Florida, Georgia, Kansas, Minnesota, New Jersey, New Mexico, Ohio, Utah, Virginia, and Washington.**

### *Spotlight on New Mexico*

New Mexico's step therapy model legislation, Senate Bill 11, has passed in the House and Senate and is waiting for Governor Susana Martinez's signature. If you live in New Mexico, you can urge Governor Martinez to sign S.B. 11 into law [here!](#)

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

### **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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