



Highlights from the Hill

May 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](#).

National Advocacy

Administration Announces Blueprint to Lower Prescription Drug Prices and Reduce Out-of-Pocket Costs

On May 11, 2018, President Trump announced a [blueprint](#) to tackle this issue of high prescription drug prices. The plan identifies several areas of reform including increasing

competition, better negotiation, lowering list prices, and reducing out-of-pocket spending for patients. The plan calls on Congress and federal agencies, such as Health and Human Services (HHS), the Food and Drug Administration (FDA), and the Centers for Medicare and Medicaid Services, to propose new strategies and take bold actions.

The Epilepsy Foundation will be monitoring the actions taken by the Administration and Congress to ensure that the voice of the epilepsy community is heard.

Take Action: Tell Congress to Preserve Funding for the Children's Health Insurance Program (CHIP)

Earlier this year, Congress passed, and the President signed, a law extending funding for the Children's Health Insurance Program for ten years. On May 8, 2018, the Administration proposed \$15 billion in rescissions, of which \$7 billion would be cut from CHIP.

The proposed rescissions would come from cutting \$2 billion from the Child Enrollment Contingency Fund, which provides payments to states if they experience an unexpected surge in enrollment due to an economic recession or public health crisis, including natural disasters. The White House also proposes to rescind \$5 billion from the Children's Health Insurance Fund.

This proposal undermines the bipartisan CHIP agreement and removes reassurances to states that funding will be available to keep kids covered. Cuts to CHIP in the past have usually been reinvested to offset other vital health care programs, which is not the case for the most recent proposed rescissions. The Epilepsy Foundation will continue to monitor the proposed cuts as Congressional members move the proposal forward.

[Tell Congress to Preserve Funding for CHIP today!](#)

Learn more about the Children's Health Insurance Program at advocacy.epilepsy.com/CHIP.

Urge Congress to Support Federal Funding for CDC Epilepsy Programs

Congress is moving forward with the FY 2019 appropriations process. 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 support \$9.5 million in funding to invest in critical epilepsy public health programs at the Centers for Disease Control and Prevention (CDC) to improve the quality of life for individuals with epilepsy.

[Take action NOW and urge Congress to support federal funding for CDC epilepsy programs for FY 2019!](#)

Read an op-ed from Phil Gattone, President and CEO of the Epilepsy Foundation, on Medicaid waivers [here](#). The Epilepsy Foundation will continue to monitor these types of waivers and we will continue to advocate for physician-driven, patient-centered care.

STATE ADVOCACY

Epilepsy Foundation Submits Comments on Several Section 1332 State Innovation Waivers

The Epilepsy Foundation has submitted comments on Section 1332 State Innovation Waivers in Louisiana, Maine, and Maryland. Section 1332 of the Affordable Care Act (ACA) allows states to apply for State Innovation Waivers to pursue innovative strategies for providing their residents with access to high-quality, affordable health insurance while retaining the basic protections of the ACA.

The Epilepsy Foundation advocates for access to quality health care that is affordable and comprehensive, and that meets the needs of individuals with serious and chronic health conditions and disabilities. A strong, robust marketplace is essential for people with epilepsy to access the coverage they need. We have submitted comments to support these states' efforts to strengthen their marketplaces by submitting 1332 State Innovation Waivers to implement reinsurance programs.

Reinsurance is an important tool to help stabilize health insurance markets. These programs help insurance companies cover the claims of very high cost enrollees, which in turn keeps premiums affordable for other individuals buying insurance on the individual market. Reinsurance programs have been used to stabilize and even to reduce premiums, as well as increase the number of individuals obtaining health insurance through the individual market. This would help patients with pre-existing conditions, including individuals with epilepsy, obtain affordable, comprehensive coverage.

Read our comments and learn more about Medicaid at advocacy.epilepsy.com/Medicaid.

Iowa: Tell Legislators to Improve the Medical Cannabis Program

Last year, the Governor signed legislation, House File 524, that created a comprehensive medical cannabis program in Iowa. Current legislation, Senate File 2405, would make much needed improvements to the medical cannabis program by eliminating the THC cap, adding eligible medical conditions, and removing the sales tax on medical cannabis. The bill would improve access for individuals living with intractable epilepsy who seek medical cannabis as a treatment option.

The Epilepsy Foundation supports safe, legal access to medical cannabis and CBD if a patient and their health care team feel that the potential benefits of medical cannabis or CBD for uncontrolled epilepsy outweigh the risks.

[Take action NOW to urge your legislators to pass SF 2405!](#)

Learn more about medical cannabis at advocacy.epilepsy.com/medical-cannabis.

Colorado: Tell Governor Hickenlooper to Sign HB 18-1187 into Law

The Colorado legislature passed legislation (HB 18-1187) that would allow therapies derived from cannabidiol (CBD) and approved by the Food and Drug Administration (FDA) to become available in the state. It is crucial to create access to innovative, FDA-approved prescription medications.

The FDA is currently reviewing at least one CBD-derived therapy, Epidiolex, that shows promise for the treatment of Dravet and Lennox-Gastaut syndromes (LGS), tuberous sclerosis complex (TSC) and potentially other rare epilepsies. The FDA Peripheral Central Nervous System Drug Advisory Committee recently voted unanimously (13-0) in support of approving Epidiolex. An FDA decision is expected in late June, after which the Drug Enforcement Agency (DEA) must take action to schedule the medication.

[Tell Governor Hickenlooper to sign HB 18-1187 into law!](#)

Follow our advocacy efforts on FDA-approved Therapies Derived from CBD at advocacy.epilepsy.com/statefdapathway.

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 so 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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