



Highlights from the Hill

April 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 April 15-17, 2018, the Epilepsy Foundation hosted our annual Public Policy Institute and Teens Speak Up! conference. Check out our Hill Day advocates!

National Advocacy

Congress Passes FY 2018 Budget

On March 23, 2018, Congress passed and the President signed the FY 2018 omnibus spending bill, H.R. 1625, into law. The bill did not include any ACA market stabilization provisions, however the \$1.3 trillion bill included increases to the State Health Insurance Assistance Program (SHIP), Social Security, and a \$3 billion funding boost to the National Institutes of Health (NIH), among many others.

As Congress moves deeper into the FY 2019 appropriations process, the Epilepsy Foundation 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 Hosts Public Policy Institute and Teens Speak Up! Conference in Washington, D.C.

We were thrilled to welcome so many members of the epilepsy community to Washington, D.C. for our annual signature advocacy event, the Public Policy Institute and Teens Speak Up! conference. The conference was held Sunday, April 15, 2018 through Tuesday, April 17, 2018.

This year we brought together more than 175 teens, parents, local office staff, members of the rare epilepsy community, policy experts, and volunteers. We had representatives from 32 chapters and affiliates across 32 states. A day and a half of learning and advocacy training culminated with a successful day on Capitol Hill, where families and state advocacy leaders shared their personal stories to raise awareness and advocate in support of federal funding for epilepsy research and programs, in more than 200 Congressional meetings.

Thank you to all participants for joining us in D.C. and for your commitment to be advocates back home. To learn more visit: advocacy.epilepsy.com/TSU2018.

Tell Congress to Support Federal Funding for CDC Epilepsy Programs

With the FY 2018 spending bill behind them for now, 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 tell Congress to support federal funding for CDC epilepsy programs for FY 2019!](#)

FDA Advisory Committee Unanimously Supports Approval of New Drug for Epilepsy, Epilepsy Foundation Testifies

On April 19, 2018, the U.S. Food & Drug Administration (FDA) Peripheral and Central Nervous System Drug (PCNS) Advisory Committee voted unanimously (13-0) in support of approving Epidiolex, a new drug treatment of Dravet and Lennox-Gastaut syndromes. Phil Gattone, President & CEO of the Epilepsy Foundation, and Polly VanderWoude, mother of Olivia, who has been part of the Epidiolex clinical trials, testified before the committee in support of the approval of Epidiolex.

Epidiolex represents hope for the many individuals living with intractable seizures and rare epilepsies. Additionally, this is a big step forward for the world of biomedical innovation and could help pave the way for more cannabis research. Epidiolex would be the first drug approved by the FDA that is derived from cannabidiol.

The Epilepsy Foundation will continue to advocate for changes in state laws required to ensure a state pathway for timely access to Epidiolex once approved by FDA. An FDA decision is expected in late June, after which the Drug Enforcement Agency (DEA) must take action to schedule the medication. Learn more about state rescheduling for FDA-approved therapies derived from CBD at advocacy.epilepsy.com/statefdapathway.

Read the Epilepsy Foundation's statement applauding the Advisory Committee's action [here](#).



The Epilepsy Foundation attended the FDA Peripheral and Central Nervous System Drug (PCNS) Advisory Committee hearing on Epidiolex (above). Phil Gattone, President & CEO of the Epilepsy Foundation, and Polly VanderWoude, testifying before the committee in support of the approval of Epidiolex (below).



Epilepsy Foundation and I Am Essential Coalition Comment on Short-Term Limited Duration Plans

On April 23, 2018, the Epilepsy Foundation and the I Am Essential coalition submitted comments to the U.S. Department of Health and Human Services regarding the proposed rule on

short-term limited duration insurance plans (STLTPs). The proposal would amend the definition of short-term limited duration plans and lengthen the maximum period of these plans from 3 months to 364 days. Additionally, STLTPs would not be required to provide certain patient protections covered by the Affordable Care Act (ACA), such as the ten essential health benefits.

We are concerned that this proposed rule, if finalized, would destabilize the individual and small employer insurance market by chipping away at key consumer protections created by the Affordable Care Act (ACA) and lead to higher premiums and cost-sharing for people with complex chronic health conditions like epilepsy.

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.

Epilepsy Foundation Comments on Proposed Rule on SNAP

On April 9, 2018, the Epilepsy Foundation submitted comments on the U.S. Department of Agriculture's (USDA) proposed rule on the Supplemental Nutrition Assistance Program. This proposal would impose additional requirements for able-bodied adults without dependents.

We are concerned with this proposed rule. People with disabilities and their families are significantly more likely to experience hunger and food insecurity compared to people without disabilities. Studies have consistently found high rates of food insecurity in households that include children with disabilities, and robust literature has found that food insecurity and inadequate food intake can negatively affect children's health and development. All too often, food insecurity and disability go hand-in-hand.

You can read the Epilepsy Foundation's comment at advocacy.epilepsy.com/ADA.



On March 29, 2018, the Epilepsy Foundation Connecticut held an advocacy day at the state capitol in Hartford!

STATE ADVOCACY

Bettyjo Bouchey, Epilepsy Foundation of Indiana, Receives 2018 Sara Stubblefield Advocacy Award

The Epilepsy Foundation was pleased to present the 2018 Sara Stubblefield Advocacy Award to Dr. Bettyjo Bouchey during this year's Public Policy Institute conference. Dr. Bouchey serves on the Board of Advisors for the Epilepsy Foundation of Indiana and as one of the State Advocacy Leaders. She is a tireless advocate for the epilepsy community in Indiana.

Her advocacy was born out of need when her son had his first seizure in 2015 and was later diagnosed with idiopathic primary, generalized epilepsy. She has remained committed to the epilepsy community and her advocacy has taken her into the boardroom, to the Indiana State legislative floor, and in 2018, her advocacy has taken her to Washington D.C. Dr. Bouchey's passion and professionalism were a strong driver for the successful passage of legislation that is paving the way for access to medical cannabis for people living with intractable epilepsy in Indiana.

The annual Advocacy Award honors the late Sara Stubblefield, who passed away in 2011 at the age of 36. Sara was diagnosed with epilepsy when she was in high school. She was known for accepting her condition with grace and for never letting it define her. A dedicated advocate for epilepsy education and research, she served for 10 years as epilepsy services coordinator for the Epilepsy Foundation of Greater Southern Illinois.



Bettyjo Bouchey with her family and Richard and Carolyn Stubblefield, parents of the late Sara Stubblefield.

Lyndsey Crunk Act Signed into Law in Kentucky

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. During their Epilepsy Advocacy Day in Frankfort on March 7, 2018, the Epilepsy Foundation of Kentuckiana and their participants advocated strongly for the passage of H.B. 147.

H.B. 147 will improve the care of students with epilepsy and seizure disorders in schools by ensuring the administration of FDA-approved medications prescribed to treat seizure disorders, require students to have a seizure action plan in their file and ensure that the action plan is properly distributed to any school personnel responsible for the supervision of the students, and

by requiring school personnel to be trained in seizure recognition and response using the Epilepsy Foundation training materials.



Epilepsy Foundation of Delaware hosted their fourth annual Epilepsy Education Luncheon on January 25, 2018 at the state capitol in Dover!

State Legislature Sessions Adjourn

The 2018 state legislature sessions have adjourned in many states. However, there continue to be a number of state legislatures that will remain open into the summer months or even until the end of the year. We will continue to monitor state legislative activity and most importantly, we want to thank everyone who has taken action! From step therapy bills to continuity of care legislation to creating access to FDA-approved therapies derived from cannabidiol, you have helped make a difference in the epilepsy community by letting your legislators hear from you.

To learn more about what happened during the 2018 legislative session in your state, please visit advocacy.epilepsy.com/states.

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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