



# Highlights from the Hill

May 2017

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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](#).

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## National Advocacy

### Preserving Access to Affordable Health Care for People with Epilepsy

On May 4, 2017, the House of Representatives passed the *American Health Care Act* (AHCA), which would repeal critical patient protections created by the Affordable Care Act (ACA), and

radically restructure the way the federal government supports state Medicaid programs. As the Senate debates and makes revisions to the AHCA, the Epilepsy Foundation will continue to advocate for meaningful access to care for all individuals living with epilepsy. In our communications with Congress, we are particularly focused on maintaining protections for people with pre-existing conditions, Essential Health Benefit requirements for insurance plans, and sufficient federal support for the Medicaid program, which one third of people with epilepsy rely on for access to health care. Take action to ask your senators to support access to affordable health care for the epilepsy community [here](#).

### **Congress to Consider Long-Term Funding Extension for the Children's Health Insurance Program (CHIP)**

For two decades, the Children's Health Insurance Program (CHIP) has been an essential source of health care coverage for American children, including many with epilepsy. CHIP provides access to high-quality, affordable health care for children in working families whose parents earn too much to qualify for Medicaid but too little to purchase private health insurance on their own. CHIP funding is currently set to expire on September 30, 2017 and swift Congressional action is needed to ensure that health care coverage for nearly nine million children who rely on CHIP will not be disrupted. The Epilepsy Foundation has joined a letter to members of Congress with many other patient groups to encourage them to quickly consider and reauthorize CHIP. We will continue to engage with members of Congress in the coming months to ensure CHIP is reauthorized.

### **Epilepsy Foundation Opposes ADA Education & Reform Act (H.R. 620)**

The House of Representatives is currently considering the *ADA Education & Reform Act of 2017* (H.R. 620), which would shift the burden for ADA compliance from business owners to people with disabilities. The Epilepsy Foundation opposes this bill and all efforts to modify the Americans with Disabilities Act (ADA) that would reduce protections for the disability community. In March, the Epilepsy Foundation joined 200 member organizations of the Consortium for Citizens with Disabilities in a letter to the House Judiciary Committee in opposition to the bill. Before the bill is scheduled for a hearing, members of the House need to hear from the epilepsy community about the importance of preserving the ADA's critical protections. Take action and tell Congress to protect the ADA [here](#). To learn more about the ADA, visit [advocacy.epilepsy.com/ADA](http://advocacy.epilepsy.com/ADA).

### **Epilepsy Foundation Encourages Congress to Reauthorize FDA User Fee Programs**

Congress is currently considering the reauthorization of the Food and Drug Administration (FDA) user fee programs, which allow the FDA to collect fees from drug and device manufacturers to fund the new drug and device approval process. The FDA user fee programs accelerate the pace of biomedical innovation and ensure that promising new treatments for epilepsy are able to quickly come to market. The user fee programs must be reauthorized in 2017 to allow the FDA to sustain its important work.

On May 4, the Epilepsy Foundation sent letters to the [Senate Health, Education, Labor and Pensions \(HELP\) Committee](#) and the [House Energy and Commerce Committee](#) in support of the user fee programs and the negotiated agreements developed by stakeholders, including patient groups, which inform the legislation. On May 11, the Senate HELP committee approved the reauthorization act by a vote of 21-2, and the bill will now head to the Senate floor for a full vote. The House Energy & Commerce Committee is still considering the bill. On May 17, the Epilepsy Foundation sent a [letter](#) to the House Energy and Commerce Subcommittee on Health prior to their markup of the bill scheduled for May 18. Learn more about why these user fee programs are so important to patients and the epilepsy community by reading our blog post [here](#).

Take action! Urge Congress to reauthorize the FDA user fee programs [here](#).

### **Senate Confirms Dr. Scott Gottlieb as FDA Commissioner**

On May 9, the Senate voted 57-42 to confirm Dr. Scott Gottlieb as Commissioner of the Food and Drug Administration (FDA). Dr. Gottlieb is a physician who previously served as Deputy Commissioner of the FDA from 2005-2007. In his new role, Dr. Gottlieb will oversee the FDA in its work to monitor the safety and efficacy of medical products, devices, and diagnostic tests, in addition to food, cosmetics, and radiation-emitting products.

### **Congress Finalizes FY 2017 Budget - Including Funding Increases for NIH and CDC**

On May 5, the President signed a \$1.07 trillion omnibus spending bill to fund federal government programs through the end of fiscal year (FY) 2017. The agreement provides \$34 billion in funding for the National Institutes of Health (NIH), which is a \$2 billion increase from FY 2016, and \$7.3 billion for the Centers for Disease Control and Prevention (CDC), a \$22 million increase from FY 2016. Several programs at the NIH and CDC that directly benefit the epilepsy community received modest funding increases, including the NIH Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative and the CDC Epilepsy Program.

### **Urge Congress to Support FY 2018 Funding for the CDC Epilepsy Program**

After finalizing the fiscal year (FY) 2017 spending bill, Congress now turns to evaluating 2018 funding levels for many government programs. The Epilepsy Foundation believes that epilepsy should be a public health priority, and supports government investment in programs that help build safer communities by educating community members and building awareness about epilepsy. We urge Congress to appropriate at least \$9.5 million for the Epilepsy Program at the Centers for Disease Control & Prevention (CDC) and have joined coalition letters to the House and Senate Appropriations Committees in support of increased funding for programs at the Departments of Labor, Education, and Health and Human Services. Ask your members of Congress to support funding for the CDC Epilepsy Program [here](#).

### **Benefits of Self-Driving Cars for the Epilepsy Community**

The Epilepsy Foundation is currently exploring the possible benefits of self-driving cars for the epilepsy community. Several automobile manufacturers and technology companies are currently developing self-driving car prototypes and some of these cars have been successfully tested on public roads. The Epilepsy Foundation supports innovation that may bring added mobility to people with epilepsy who cannot drive, and encourages the federal government and state legislatures to take proactive steps to stimulate development in this field. Would you or someone you know benefit from self-driving cars? Share your story with us by emailing [tsu@efa.org](mailto:tsu@efa.org).

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## **State Advocacy**

### **Pennsylvania Op-Ed on Access to Epilepsy Medications in Drug Monitoring Programs**

On April 28, *The Intelligencer* and *The Times-Tribune* newspapers published an op-ed by Epilepsy Foundation of Western/Central Pennsylvania President & CEO, Peggy Beem and Brad Klein, MD, a neurologist and member of the Alliance for Patient Access' Physicians Neurological Disease Working Group, urging Pennsylvania lawmakers to support H.R. 395, a bill that would improve access to some scheduled epilepsy medications in Pennsylvania. The op-ed highlights how the state's prescription drug monitoring program -- while a valuable tool in addressing the opioid epidemic, could create unnecessary barriers to lifesaving epilepsy medications. H.R. 395 would exempt Schedule V non-opioid, non-narcotic medications -- which are epilepsy medications -- from the state PDMP. Read the op-ed [here](#), and learn more about this issue by visiting [advocacy.epilepsy.com/efa/PDMP](http://advocacy.epilepsy.com/efa/PDMP).

### **Step Therapy Advocacy Update: Iowa**

#### **Iowa Step Therapy Bill Signed into Law**



On May 10, Iowa Governor Terry Branstad signed House File 233 into law, placing limits on step therapy protocols used by insurance companies in Iowa. Under the new law, insurers are required to provide a clear appeals process for step therapy requirements and must allow patients and their physicians to override these requirements when medically necessary. During the 2017 legislative sessions, similar legislation was introduced

in nearly half of the states and has already been signed into law in Arkansas and West Virginia. To learn more about step therapy, visit [advocacy.epilepsy.com/StepTherapy](http://advocacy.epilepsy.com/StepTherapy).

### **Cannabidiol (CBD) Advocacy Update: Laws Enacted in Indiana, Arizona and Wisconsin**

#### **Indiana Governor Eric Holcomb Signs CBD Access Bill into Law**

On April 26, Indiana Governor Eric Holcomb signed House Bill 1148 into law, allowing Indiana residents to use cannabidiol (CBD) as a potential treatment option for epilepsy, legally under state law. The Epilepsy Foundation and the Epilepsy Foundation of Indiana are thrilled that the

Hoosier state has taken the first step towards securing safe, legal access to CBD for individuals with epilepsy and encourage Governor Holcomb and the Indiana General Assembly to take the next step by establishing a state-regulated program that allows for cultivation, production and dispensing of medical cannabis and CBD in Indiana.

### **Arizona Enacts Law to Facilitate Access to FDA-Approved Therapies Derived from CBD**

On April 24, Arizona Governor Doug Ducey signed Senate Bill 1377, allowing any medication derived from CBD that is approved by the FDA and rescheduled by the DEA to be prescribed to Arizona residents. In February, Epilepsy Foundation of Arizona Executive Director Suzanne Matsumori testified in favor of Senate Bill 1377 at the State Capitol.

### **Wisconsin Expands Legal Access to CBD and CBD-Derived Therapies**

On April 18, Wisconsin Governor Scott Walker signed Senate Bill 10, expanding state law to allow Wisconsinites with any medical condition to use CBD with a physician's recommendation. Senate Bill 10 also ensures that any therapy derived from CBD that is approved by the FDA will be available in Wisconsin. While the Epilepsy Foundation encourages the Wisconsin legislature to go further in exploring a comprehensive, state-regulated program that allows for cultivation, production and dispensing of medical cannabis and CBD, Senate Bill 10 is an important step forward for access to medical cannabis in Wisconsin.

All states need to take action, whether through regulatory or legislative changes, to create a state pathway so residents can access FDA-approved therapies derived from CBD because CBD is a Schedule I substance at the federal level. Follow our efforts to accomplish these changes at [advocacy.epilepsy.com/statefdapathway](https://advocacy.epilepsy.com/statefdapathway).

### **Medication Synchronization Advocacy Update: Oklahoma and Georgia**

On May 1, Oklahoma Governor Mary Fallin signed House Bill 1824 into law, making it easier for individuals living with epilepsy and other chronic conditions to refill multiple prescriptions on the same day each month and ensure that costs are appropriately pro-rated. On May 9, Georgia Governor, Nathan Deal signed Senate Bill 200, creating similar medical synchronization provisions for Georgia residents. Having to make several trips to the pharmacy can make it harder for people to refill and stay on their medications. The Epilepsy Foundation strongly supports legislation like House Bill 1824 and Senate Bill 200 that allows people to align their medication refills. Medication synchronization is especially important for some people with chronic conditions like epilepsy who cannot drive themselves to the pharmacy.

To learn more about medical synchronization, visit [advocacy.epilepsy.com/efa/MedSync](https://advocacy.epilepsy.com/efa/MedSync).

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