



Highlights from the Hill

March 2017

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As the state and federal legislative sessions progress, 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 epilepsy throughout the year. Growing our advocacy network is critical to achieving our public policy goals as we head into busy state and federal legislative sessions. Make a difference today by sharing our Speak Up, Speak Out! Network on **Facebook** and **Twitter**.

National Advocacy

Epilepsy Foundation Concerned with Provisions in American Health Care Act that Could Undermine Access to Care for People with Epilepsy

Congress is currently considering legislation, entitled the American Health Care Act (AHCA), that would repeal and replace the Affordable Care Act (ACA). The Epilepsy Foundation is closely monitoring the progress of the AHCA and other health care reform proposals under consideration by Congress, and participating in the policy discussions. We are particularly concerned with a proposal within the AHCA to limit federal support for state Medicaid programs. Medicaid provides lifesaving medications and services for more than a third of people living with epilepsy, including children from low-income families and/or with severe forms of epilepsy, as well as children and adults living with disabilities.

As the debates over health care reform continue, the Epilepsy Foundation will continue to advocate for access to affordable, quality care for individuals living with epilepsy. We will continue to communicate with Congress and the Administration regarding the numerous ways that the ACA has benefited our community, and make clear the provisions that we would need in future health care reform efforts. In January, we sent a letter to President Trump and Congressional leadership, detailing the key provisions of the ACA that must be preserved. Read the letter [here](#).

As part of the Epilepsy Foundation's engagement in these policy discussions on access to quality care, we want to hear about your experiences with health insurance coverage. Are you able to access the medications, specialists, and services you need? **Tell us your story by completing our Access to Care survey:** advocacy.epilepsy.com/efa/ACA/survey

Epilepsy Foundation Urges Congressional Leaders to Protect Medicaid

On March 3, 2017, the Epilepsy Foundation signed a coalition letter that was sent to Congressional leaders to urge them to reject proposals to reduce the amount of funds available to the states for Medicaid programs. Under proposed replacements for the Affordable Care Act, up to \$370 billion in Medicaid funding for state programs could be cut over the next ten years in a massive restructuring of the Medicaid program. More than ten million older adults and people with disabilities rely on Medicaid for their health care and medication needs, including many with epilepsy.

The Epilepsy Foundation is dedicated to protecting Medicaid and opposing measures that reduce the Medicaid program's coverage and funding for people with epilepsy. In signing the coalition letter, the Epilepsy Foundation joined 100 other organizations representing older Americans and people with disabilities. Read the letter [here](#).

Epilepsy Foundation & I Am Essential Coalition Comment on Proposed ACA Market Stabilization Rule

On March 7, 2017, the Epilepsy Foundation and the I Am Essential coalition submitted comments on a proposed Department of Health and Human Services (HHS) rule related to the

insurance market created by the Affordable Care Act (ACA). The proposal would bring changes to the rules of business within the ACA Marketplaces including the length of open enrollment periods, processes around special enrollment periods, and actuarial value requirements for particular plans.

The I Am Essential letter urges HHS and/or the insurers to share evidence of any suspected abuse of the current marketplace, and explore the impact of the proposed changes more carefully before moving forward with the proposed rules. The proposed changes have the potential to discourage individuals from obtaining health care coverage, especially the young, healthy individuals who are necessary to help ensure robust risk pools. Imposing ever-higher bureaucratic barriers to enrollment has already been shown to discourage healthy young people from enrolling and would ensure that only those most desperate for coverage would enroll, worsening the risk pool. Read the I Am Essential Letter [here](#).

Epilepsy Foundation & the Consortium for Citizens with Disabilities Oppose ADA Education and Reform Act of 2017 (H.R. 620)

On March 13, 2017, the Epilepsy Foundation joined more than 200 member organizations of the Consortium for Citizens with Disabilities in a letter to the House Judiciary Subcommittee on Constitution and Civil Justice. The letter expressed strong opposition to the ADA Education and Reform Act of 2017 (H.R. 620), which would create significant obstacles for people with disabilities to enforce their rights under Title III of the Americans with Disabilities Act (ADA) to access public accommodations, and would impede their ability to engage in daily activities and participate in the mainstream of society. Under the bill, the burden of protecting the right to access a public place would shift to people with disabilities, who would be required to first be denied access to a facility, then determine that violation of the law has occurred, then provide the facility with notice of the specific law that was violated. Read the letter to the House Judiciary Subcommittee on Constitution and Civil Justice [here](#).

Epilepsy Foundation's Angela Ostrom Participates in Epilepsy Q&A for Rare Diseases Day

As part of activities to recognize Rare Diseases Day (February 28, 2017), the Epilepsy Foundation's Angela Ostrom (Chief Legal Officer & Vice President of Public Policy) participated in a Q&A with PhRMA that highlights the Foundation's work to improve the lives of people living with rare epilepsies.

More than 7,000 rare diseases impact 30 million Americans - including about a million people living with uncontrolled seizures that are often the result of rare epilepsies. The rare epilepsies community has come together to create the first ever Rare Epilepsy Network (REN), with seed funding from the Patient-Centered Outcomes Research Institute (PCORI). The REN is a patient registry designed to collect information about people living with rare epilepsies to better understand these conditions and inform research into therapies that can improve the lives of people living with rare epilepsies.

Learn more about the challenges that the epilepsy community faces and the opportunities before us as we invest in research and support policies that can unleash the promise of innovation by reading the Q&A [here](#).

Epilepsy Foundation Opposes Bill Allowing Employers to Request Genetic Information

As a strong supporter of civil rights laws that ensure protections for people with epilepsy, the Epilepsy Foundation is committed to opposing legislation that endangers the privacy of personal genetic information. On March 8, 2017, the Foundation signed a letter sent to the U.S. House Committee on Education and the Workforce in opposition to H.R. 1313, a bill that would exempt employer-based wellness programs from genetic nondiscrimination provisions in the Genetic Information Nondiscrimination Act (GINA) and the Americans with Disabilities Act (ADA).

Under current law, employers cannot impose penalties on employees who choose not to disclose their genetic information. However, H.R. 1313 would allow employers to condition discounts or payment on insurance premiums on the disclosure of such information as part of participation in employee wellness programs. This could result in a loss of up to several thousand dollars per year for an employee. This structure could essentially coerce employees into revealing their private genetic information, and make it easier for employers to discriminate based on employee genetic factors. Read our letter opposing H.R. 1313 [here](#).

Seema Verma Confirmed as Centers for Medicare & Medicaid Services Administrator

On Monday, March 13, 2017, the Senate confirmed Seema Verma as administrator of the Centers for Medicare & Medicaid Services (CMS) by a vote of 55-43. CMS is responsible for Medicare and federal components of the Medicaid program, as well as the marketplaces and rules under the ACA. Verma has a background working on the Medicaid expansion for the state of Indiana and is expected to be actively involved in the conversations around changes to Medicaid. She will be an important contact in the new administration.

Dr. Scott Gottlieb Nominated for Food and Drug Administration Commissioner

On Friday, March 10, 2017, President Trump nominated Dr. Scott Gottlieb to fill the top position at the Food and Drug Administration (FDA). Gottlieb is a physician who has served in a deputy role in the FDA in the past.

In February, Epilepsy Foundation Board Member and former Congressman Tony Coelho wrote an op-ed for *The Hill* that detailed the importance of having a qualified FDA Commissioner for the epilepsy community. Read the op-ed [here](#).

State Advocacy

Keep Track of Advocacy Efforts in your State

Remember to keep track of state-specific legislative issues on your state page, which can be accessed [here](#). We continually update these pages, especially during the current legislative sessions.

Epilepsy Foundation Advocates for State Bills to Align Medication Refills

People living with epilepsy often take multiple medications to maintain seizure control and manage co-morbidities. Having to make multiple trips to the pharmacy to fill prescriptions makes it difficult for people to maintain a consistent supply of medication and can lead to missed doses, breakthrough seizures and other medical complications. Medication Synchronization allows pharmacists to work together with doctors and people with epilepsy to ensure that all medications can be refilled on the same day - eliminating the need for multiple trips to the pharmacy and making medication compliance easier.

During the 2017 state legislative sessions, the Epilepsy Foundation has been advocating for legislation across the states that would make it easier for pharmacists to help people synchronize their medication refills. We have written joint letters with local Epilepsy Foundation affiliates in favor of these bills in several states including Florida, North Carolina, Oklahoma, Tennessee, and Texas. Read more about our advocacy on this issue by clicking [here](#).

Protecting Access to Epilepsy Medications in State Medicaid Programs

Spotlight on Indiana

Epilepsy medication in Indiana had historically enjoyed a protection under the state's Medicaid fee-for-service and managed care programs as an extension of protections for mental health medications. However, in 2016, the Indiana Medicaid Drug Utilization Review (DUR) Board abruptly adopted formulary changes to remove this protection in the managed care program. Since this time, the Epilepsy Foundation and local affiliates have been working to reinstate this protection. Limiting access to lifesaving medications and interrupting proven treatment regimens due to drug formulary changes can result in harmful changes to patient therapies, and are often far costlier to the Medicaid program in the long run. The Epilepsy Foundation of Indiana and the Epilepsy Foundation of Kentuckiana took the lead on this issue and had several meetings with the administration and legislators in Indiana to find a solution to this issue. Follow the ongoing work [here](#).

Spotlight on New York

In the New York State Medicaid program, a policy called "prescriber prevails" has historically allowed medical providers and patients to have final say over medication decisions. This policy protects physician-directed care, and prevents the medication switching and delays that can be dangerous for people with epilepsy. However, in his 2018 budget proposal, Governor Andrew Cuomo has included a provision that would eliminate "prescriber prevails" for epilepsy medications and other drugs. The Epilepsy Foundation is strongly opposed to this provision, and wrote a [letter](#) to Governor Cuomo on January 24, 2017, urging him to reconsider his proposal to eliminate prescriber prevails. The Epilepsy Foundation affiliates in New York continue to advocate to preserve the protections for epilepsy medications in the state Medicaid program.

Thank you to 40 epilepsy advocates in our Speak Up, Speak Out! Network that wrote to their legislators in favor of protecting prescriber prevails. Advocacy efforts have been successful thus far as the legislature did not include the cut to prescriber prevails in their budget bills.

Advocacy Update: State Pathways for FDA Approved Therapies Derived from CBD

In 2017, one of the Epilepsy Foundation's major advocacy priorities has been ensuring the creation of state pathways to allow therapies derived from cannabidiol (CBD) and approved by the Food and Drug Administration to become available to patients in a timely manner.

The 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 for Dravet syndrome and also Orphan Drug Designation for LGS and TSC, another type of rare epilepsy. Given the Fast Track Designation, this potential treatment option could be available as soon as early 2018. However, without state action, therapies like this would not be available for people living with epilepsy. In some states this specific rescheduling change can be accomplished through administration actions while in other states it requires legislation. To learn more about this issue and our efforts, click [here](#).

Spotlight on Arkansas

Governor Hutchinson signs CBD Rescheduling Bill Into Law!

On March 15, 2017, Governor Asa Hutchinson of Arkansas signed House Bill 1402 into law, directing the Arkansas Department of Health to consider the rescheduling of marijuana-based substances that are approved by the FDA. Bridgit Patterson, a program director with the Kansas City office of the Epilepsy Foundation of Missouri & Kansas was present at the signing ceremony for House Bill 1402.



(Photograph courtesy of Derrick Rose)

Advocacy Update: Step Therapy Legislation

During the 2017 state legislative sessions, the Epilepsy Foundation has been advocating strongly for bills intended to limit step therapy requirements imposed by insurance companies on people with epilepsy and other conditions. As of March 16, 2017, these step therapy bills have been introduced in 17 states, including Colorado, Georgia, Florida, Hawaii, Iowa, Kansas, Maine, Massachusetts, New Mexico, Ohio, Oregon, Rhode Island, Texas, Virginia, Utah, Washington, and West Virginia. To learn more about this issue and our efforts, visit [here](#).

Advocacy Update: Medical Cannabis Legislation

The Epilepsy Foundation is committed to supporting physician-directed care, and to exploring and advocating for all potential treatment options for epilepsy, including cannabidiol (CBD) oil and medical cannabis. We support safe, legal access to medical cannabis if a patient and their health care team feel that the potential benefits of medical cannabis for uncontrolled epilepsy outweigh the risks.

Spotlight on Iowa

To extend the life of Iowa's existing CBD program, State Representative Clel Baudler has introduced House Study Bill 164, which would repeal the sunset provision in Iowa's current CBD law. If this provision is not repealed, Iowa's CBD program will expire in July 2017, leaving no legal way for people with epilepsy in Iowa to use CBD. The Epilepsy Foundation and the Epilepsy Foundation of North/Central Illinois, Iowa & Nebraska are strongly in favor of House Study Bill 164. Read our letter of support for House Study Bill 164 [here](#).

Additionally, the Epilepsy Foundation and the Epilepsy Foundation of North/Central Illinois, Iowa & Nebraska are supporting Senator Brad Zaun's bill, Senate Study Bill 1176, which would establish a comprehensive, state-regulated medical cannabis program. This is the only way to ensure that Iowa residents living with epilepsy and uncontrolled seizures could gain safe, legal access to medical cannabis as a treatment option. Read our letter of support for Senate Study Bill 1176 [here](#).

Spotlight on South Carolina

In South Carolina, the Epilepsy Foundation is strongly in favor of Senate Bill 212, which would ensure South Carolinians living with epilepsy and uncontrolled seizures can gain safe, legal access to medical cannabis as a treatment option. The bill would create a comprehensive medical cannabis program, accessible to individuals with debilitating medical conditions after consultation with a physician. The program would be regulated by the South Carolina Department of Health and Environmental Control, and would include a licensing structure for establishments to cultivate, process, dispense, and test medical cannabis. Read our letter of support for Senate Bill 212 [here](#).

Advocacy Update: Removing Barriers to Epilepsy Medications in State Drug Monitoring Programs

State Prescription Drug Monitoring Programs (PDMP) are intended to curb prescription drug abuse. Schedule V epilepsy medications, which are not opioids or narcotics, do not pose the risk for abuse associated with other Scheduled medications. Individuals living with epilepsy who experience a delay in accessing their medication due to onerous drug monitoring requirements are at a high risk for developing breakthrough seizures and related complications. The Epilepsy Foundation supports exempting Schedule V epilepsy medications from state Prescription Drug Monitoring Programs in states across the country. Read more about our advocacy on this issue [here](#).

Spotlight on Pennsylvania

In Pennsylvania, Representative Gene DiGirolamo has introduced House Bill 395, a bill that would amend the Achieving Better Care by Monitoring All Prescriptions Program (ABC-MAP) to remove non-opioid, Schedule V drugs from the state prescription drug monitoring program. On February 27, 2017, the Epilepsy Foundation and our affiliates in Pennsylvania sent a letter to the Pennsylvania House Human Services Committee in support of House Bill 395. Read our letter of support for this bill [here](#).

More than 130 members of our Speak Up, Speak Out! Network reached out to their legislators in support of the bill, which unanimously passed out of committee on Monday, March 13, 2017. Live in Pennsylvania? Write to your legislators about House Bill 395 by clicking [Take Action](#).

Spotlight on North Carolina

In North Carolina, the Epilepsy Foundation and our state affiliate are urging the North Carolina General Assembly to amend House Bill 243, a bill that would establish a prescription drug monitoring program in the state. As currently written, the bill includes non-opioid, Schedule V drugs, and would severely impact access to treatment for people living with epilepsy. On March 10, 2017, the Epilepsy Foundation sent a letter to four North Carolina State Representatives, urging them to exempt Schedule V medications from the monitoring requirements of House Bill 243. Read our letter of concern on House Bill 243 [here](#).

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