



Highlights from the Hill

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National Advocacy

Epilepsy Foundation Signs onto Statement with Patient Advocacy Groups on Proposed Pre-Existing Condition Legislation

More than 25 patient advocacy organizations, including the Epilepsy Foundation, released a [statement](#) on September 4, 2018 regarding the *Ensuring Coverage for Patients with Pre-Existing Conditions Act* (S. 3388). The legislation was introduced in response to *Texas v. U.S.*, a lawsuit brought by 20 states and two individual plaintiffs arguing that the court must invalidate the entire Affordable Care Act (ACA) due to Congress' repeal of the individual mandate in the *Tax Cuts and Jobs Act of 2017*. S. 3388 is intended to address the impact on patients if the court overturns protections under current law. In addition to the statement, the Epilepsy Foundation, along with 32 groups, signed onto a [letter](#) to the cosponsors of S. 3388 outlining our concerns.

We applaud the sponsors of the legislation for recognizing the importance of protecting access to care for those with pre-existing conditions and prohibiting the denial of coverage. However, we are concerned that the legislation would not ban pre-existing condition exclusions. While the bill protects against higher rates based on health status, the bill does not protect against higher rates based on such factors as age, gender, and occupation, all of which can be used as proxies for health status. Without those protections, consumers could still face higher premiums and out-of-pocket costs. The bill would not replace comprehensive protections currently covered by the Affordable Care Act (ACA) and would therefore not provide adequate, affordable, and accessible care that individuals need and deserve.

Read more about our efforts on the ACA and protecting patients with pre-existing conditions at advocacy.epilepsy.com/ACA.

Congress Forges Ahead on Health Spending Package

Congress is on target to pass the fiscal year 2019 spending bill that encompasses appropriations for the departments of Defense, Labor, Education and Health and Human Services (HHS) before the September 30, 2018 deadline. On September 18, 2018, the Senate adopted the conference report for the \$855 billion spending bill (H.R. 6157) by a 93-7 vote. The House is expected to pass the conference report next week and send the bill to President Trump. Attached to H.R. 6157 is a continuing resolution running through December 7, 2018 which will help to avoid a partial government shutdown of agencies without full-year appropriations by the September 30th deadline. This would be the first time in a decade that the Pentagon was funded on time and the first time in over two decades since appropriations for the departments of Labor, Education, and HHS were enacted before the deadline.

The House and Senate agreed to go to conference with each other over the two-bill package in early September. The bipartisan conference committee moved forward with the Senate's allocation levels, resulting in about a \$2 billion increase in funding for HHS in fiscal year 2019 from fiscal year 2018. The Epilepsy Foundation applauds Congress' efforts to pass this minibus in a timely manner. We thank all the grassroots advocates who took action and reached out to their members of Congress to advocate for federal funding for epilepsy research and programs. We will continue to monitor the appropriations process.

Learn more about federal funding for epilepsy programs and research at advocacy.epilepsy.com/federal-funding-for-epilepsy.

Epilepsy Foundation Comments on CMS Proposed Rule

On September 10, 2018, the Epilepsy Foundation submitted a [comment](#) to Seema Verma, Administrator of the Centers for Medicare and Medicaid Services, regarding proposed changes to the Medicare Physician Fee Schedule for 2019. We commend the agency's goal to reduce paperwork and unnecessary administrative tasks, however we are concerned that the proposal to collapse payments will devalue specialty care, especially for those with chronic conditions such as epilepsy, and create additional access barriers. In addition, we are concerned that the proposed changes to consolidate services will devalue the time of physicians who treat individuals with epilepsy. The creation of add-on codes would lead to new and significant administrative burdens for specialists, such as neurologists and epileptologists, undermining the original intent of reducing paperwork and potentially reducing the amount of time spent treating patients. Due to the complex and individualized nature of epilepsy and related comorbidities, we believe that the physicians' time would be better spent with a patient than on paperwork. Many industry groups also fear the proposed changes and rejected the rule in their comments. The American Medical Association, along with 170 medical groups, submitted a [letter](#) to Administrator Verma expressing similar concerns. The final rule is expected by November 1, 2018.

Learn more about our advocacy efforts on Medicare at advocacy.epilepsy.com/Medicare.

Senate Passes “Gag Clause” Prohibition Legislation, House Passes Similar Legislation Out of Committee

On September 17, 2018, the Senate passed legislation, S. 2554, that would ban pharmacy “gag clauses” in the commercial market by a 98-2 vote. Earlier in September, the Senate passed a similar measure, S. 2553, banning gag clauses in Medicare plans. Gag clauses are often inserted into contracts between pharmacy benefit managers (PBMs) and pharmacists. These clauses restrict pharmacists from informing customers when they can save money on their prescriptions by paying with or without their insurance. The House Energy and Commerce Committee approved a similar piece of legislation, H.R. 6733, on September 13, 2018. The House bill combines the prohibition of gag clauses in the private insurance and Medicare markets.

The Epilepsy Foundation supports these bills and believes that individuals deserve affordable access to the treatment their providers have determined they need, and access should not be dependent on the type of insurance they carry. Occasionally, for some individuals or some therapies, it can be less expensive for a patient to purchase the medication outside of their healthcare plan. We believe pharmacists should be free to speak to customers about all available options, particularly if an individual is inquiring about alternative ways to afford a therapy or to save money on their treatment regimen. Epilepsy medications are the most common and cost-effective treatment for controlling and/or reducing seizures, so it is imperative that prescription medications remain accessible and affordable.

Epilepsy Foundation Implores Drug Enforcement Agency to Act on Scheduling Epidiolex®

On September 14, 2018, the Epilepsy Foundation sent letters to Attorney General Jeff Sessions, Deputy Attorney General Rod Rosenstein, and Uttam Dhillon, the Acting Administrator of the Drug Enforcement Agency, asking them to promptly take action to reschedule Epidiolex® as the

90-day deadline approaches so that patients can finally gain access to this new therapy. Epidiolex® was approved by the Food and Drug Administration (FDA) in late June 2018. It is the first drug derived from cannabidiol (CBD) and is considered a Schedule I substance under the Controlled Substance Act. We are concerned about the DEA's prolonged consideration of this new therapy given that it is approved for the treatment of Lennox-Gastaut and Dravet Syndromes, both of which are rare and life-threatening forms of epilepsy. We hope that the letters instill the risks associated with not having timely access to this medication. The Epilepsy Foundation will continue to monitor the situation.

Read the letters and learn more about our advocacy efforts on FDA-approved therapies derived from CBD at advocacy.epilepsy.com/statefdapathway.

90 Patient Groups Submit Letter to CVS Health

On September 12, 2018, the Epilepsy Foundation joined 90 stakeholder groups in a [letter](#) to CVS Caremark in response to a cost-effectiveness program announced in August. The policy would allow new insurance plans to exclude coverage of drugs if they exceed a certain cost threshold. In particular, we are concerned that CVS is relying on a deeply flawed value assessment model from the Institute for Clinical and Economic Review (ICER) to deny coverage of drugs if they do not meet a subjective “quality-adjusted-life-year” (QALY)-based threshold.

The QALY-based threshold is a one size fits all measurement of health outcomes based on the overall population. This analysis ignores the important differences in individual patient needs and preferences, and in effect values individuals in “perfect health” more highly than those with a chronic illness or disease. Instead of promoting the deeply personal, individual health care decisions between a patient and their provider, this assessment favors an impersonal algorithm that discriminates against the chronically ill, the elderly and people with disabilities. We oppose such practices of limiting access to care based on cost-effectiveness studies which discriminate against patients and special populations.

Learn more and read CVS' response at advocacy.epilepsy.com/value.

Epilepsy Foundation Celebrates 15th Anniversary of Medicare Part D

On September 18, 2018, MAPRx (Medicare Access for Patients Rx), a coalition convened by the Lupus Foundation of America consisting of more than 55 patient, family caregiver, and health professional organizations including the Epilepsy Foundation, hosted a summit to celebrate the 15th anniversary of Medicare Part D. Policymakers, health care experts, and patient advocates convened for the half-day summit to discuss current challenges facing the Part D program and how to help protect and strengthen the program for the future. The event culminated in a keynote discussion with President George W. Bush, who signed the original legislation into law in 2003.

Learn more about our advocacy on Medicare issues at advocacy.epilepsy.com/Medicare.



President George W. Bush (left) with President Stevan W. Gibson (right), President of the Lupus Foundation of America, during the MAPRx summit celebrating the 15th anniversary of Medicare Part D on September 18, 2018.

STATE ADVOCACY

Epilepsy Foundation of Utah Works Toward Expanding Medicaid through Ballot Initiative

During the upcoming election, Utahns have the opportunity to vote on Proposition 3, a ballot initiative, which would expand Medicaid access in the state if passed. The Epilepsy Foundation of Utah is supporting this initiative. Under the Affordable Care Act, 34 states, including the District of Columbia, have already expanded Medicaid. Expanding Medicaid in Utah would help to provide access to health care to 150,000 working Utahns, including those with chronic illnesses like epilepsy, who earn under \$17,000 a year individually or less than \$34,000 per year for a family of four. They make too much to be eligible for traditional Medicaid and make too little to afford coverage under the Affordable Care Act marketplace. Proposition 3 would help to ensure people in Utah, especially those with chronic conditions, have adequate health care coverage so that they can afford their medications and get the care they deserve.

Read an op-ed on this topic in the Salt Lake Tribune by Margo Thurman, Executive Director of the Epilepsy Foundation of Utah [here](#).

Epilepsy Foundation Urges Open Access to Epilepsy Medications in Nevada and Vermont

The Epilepsy Foundation is urging the Pharmacy and Therapeutics Committee in Nevada and the Drug Utilization Review Board of Vermont to maintain open access to epilepsy medications – anticonvulsants - on the state Medicaid preferred drug list. Epilepsy medications are not interchangeable, and treatment is highly individualized. We oppose formulary changes that would severely restrict access and any policies that would require multiple failures or prior authorization before non-preferred medication can be secured. Failure to have access to the appropriate medication can result in increased or breakthrough seizures, injury, accidents, additional medication and hospitalization costs, loss of earnings, and unexpected death.

Read the Nevada Pharmacy and Therapeutics Committee letter [here](#).

Read the Vermont Drug Utilization Review Board letter [here](#).

Visit advocacy.epilepsy.com/states to find out what is going on in your state.

Delaware Creates Pathway for FDA-approved Therapies Derived from CBD

On August 29, 2018, Governor Carney signed House Bill 401 into law. Delaware is now the seventh state during the 2018 legislative session to create a pathway for FDA-approved therapies derived from CBD. With the recent approval of Epidiolex®, it will become very important for states that require rescheduling of therapies derived from CBD legislatively to act. The Epilepsy Foundation is committed to supporting such legislation in the upcoming 2019 state legislative session.

Learn more about our advocacy efforts at advocacy.epilepsy.com/statefdapathway.



On August 29, 2018, Valerie Budishak, Executive Director of Epilepsy Foundation of Delaware attended a ceremonial signing of House Bill 401. From left to right (top), Representative Debra Heffernan, Dr. Sarah Mullins, Valerie Budishak, and Dr. S. Charles Bean. Governor Carney is pictured seated at the table.

Continuity of Care Bill Signed into Law in Illinois

On August 24, 2018, Governor Rauner signed House Bill 4146 into law. This bill will prevent insurers from changing the medications they cover during the plan year. Without this bill, health plans are free to end or change coverage for a particular medication mid-year. Changes to health plans mid-year are concerning to the epilepsy community because epilepsy medications are not interchangeable, and individuals rely on them to maintain seizure control. To change, limit, or deny access to medications could be extremely dangerous.

[Read the September Issue of the Research Quarterly!](#)

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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