



# Highlights from the Hill

October 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

### **UPDATE: ACA and the Congressional Health Care Debate**

Earlier this week, Senators Alexander and Murray, leaders of the Senate Committee on Health, Education, Labor and Pensions, announced a bipartisan agreement on a bill to stabilize the Affordable Care Act (ACA) Marketplace. The committee's proposal would extend cost-sharing reduction (CSR) payments, and includes other mechanisms of stabilization. CSRs help low income individuals and families (who make up to 250% of the federal poverty line) cover out-of-pocket health care costs like deductibles and copays for plans offered in the ACA Marketplace.

The proposal would also preserve and support key protections for individuals with pre-existing conditions.

The Epilepsy Foundation, as part of the I Am Essential coalition, has [applauded](#) the HELP committee's bipartisan efforts, which included summer hearings with a variety of stakeholders like Governors and Insurance Commissioners. We look forward to engaging in the next steps of this process with the broader patient community - which will include a thorough and ongoing review of this proposal's impact on patients and consumers as the bill moves through regular order.

The Alexander-Murray deal signals a move away from partisan proposals to "repeal and replace" the ACA that also included reforms to Medicaid - on which more than a third of people living with epilepsy rely on for their care. On September 26, 2017, Senate leadership and the authors of the most recent "repeal and replace" proposal, Sens. Graham and Cassidy, held a press conference to announce that they would not hold a Senate floor vote on their proposal prior to September 30 deadline - the last day when they could have moved forward on a bill with only 50 votes, as opposed to the usual 60 votes required to move bills forward in the Senate.

That bill, referred to widely as Graham-Cassidy, was similar to other proposals defeated this summer. It would have drastically cut federal funding for the Medicaid program and would have allowed some insurance plans to drop coverage for basic services, including emergency care, prescription medications, and chronic disease treatment. The Epilepsy Foundation partnered with many other patient and disability advocacy groups to raise awareness of the negative consequences proposals to strip away patient protections and make deep cuts to Medicaid would have on the epilepsy community. We sent [letters](#), engaged our grassroots community, and helped build momentum in D.C. to ensure this misguided proposal did not move forward.

Continue to follow the debate and learn more about the Affordable Care Act at [advocacy.epilepsy.com/ACA](http://advocacy.epilepsy.com/ACA) and Medicaid at [advocacy.epilepsy.com/Medicaid](http://advocacy.epilepsy.com/Medicaid).

### **Administration Moves on Health Care ACA Changes**

On October 12, 2017, President Trump issued an executive order that directs agencies to make changes to current implementation of the Affordable Care Act (ACA). Federal agencies will need to issue rules in order to effectuate this order. This executive order would encourage association health plans to enter the insurance market and change the rules governing the length and renewability of short-term catastrophic health insurance plans. Allowing some plans to not cover comprehensive benefits would further destabilize the individual insurance market because costs for plans that do cover Essential Health Benefits would then skyrocket - and these are the plans that people with serious health needs rely on for meaningful coverage.

The Epilepsy Foundation joined a statement with many others in the patient community in opposition to this executive order. Read the statement [here](#).

### **Administration Announced Discontinuation of ACA CSR Payments**

On October 12, 2017, President Trump announced that the administration would no longer continue the cost sharing reduction (CSR) payments, which help low income individuals and families (who make up to 250% of the federal poverty line) cover out-of-pocket health care costs like deductibles and copays for plans offered in the ACA Marketplace.

The Epilepsy Foundation joined a statement with many others in the patient community expressing concern for this decision and urging Congress to fund this program. Read the statement [here](#). We are encouraged that Congress has since moved forward in discussions to extend the CSR payments on their own.

### **UPDATE: Children's Health Insurance Program (CHIP)**

Congress missed the September 30 deadline for funding an extension for the Children's Health Insurance Program (CHIP), which provides health insurance to 8.9 million American children. CHIP is a critical health care option for children in families that earn too much to qualify for Medicaid, but too little to purchase other private insurance. Congress must move quickly to reauthorize CHIP or states will soon be forced to reduce enrollment and cut benefits. Some states like Utah and Minnesota have already begun making cuts and changes.

On October 4, 2017, after House and Senate committees approved bills to reauthorize funding, the Epilepsy Foundation sent [letters](#) thanking committee leadership for support of the program and asking them to urge floor consideration immediately. CHIP has bipartisan support, but it hasn't yet received time before the full House and Senate bodies. Ask your members of Congress to support CHIP today - [ACT NOW!](#)

Read more about CHIP at [www.epilepsy.com/article/2017/9/its-time-fund-health-insurance-kids-again](http://www.epilepsy.com/article/2017/9/its-time-fund-health-insurance-kids-again).

### **Massachusetts and the Future of Medicaid**

Massachusetts is pursuing changes to its Medicaid program that would set a terrible precedent for limiting access to medications in Medicaid programs across the country, especially for people living with complex chronic and rare conditions. The proposal to amend Massachusetts's Medicaid (MassHealth) waiver is currently before the Centers for Medicare and Medicaid Services (CMS). If approved, other states could quickly pursue similar proposals for their Medicaid programs. More than a third of people living with epilepsy rely on Medicaid for access to the medications and services that they need to manage their conditions and maintain their quality of life.

One aspect of the proposal would create a closed formulary that would ensure coverage of just one drug per therapeutic class, while another aspect of the proposal would limit access to innovative new therapies approved by the FDA via expedited pathways by subjecting these new medications to an additional review. Epilepsy medications are not interchangeable and access to new and innovative therapies is particularly important for the more than one million people living with intractable or uncontrolled seizures and severe forms of epilepsy. There currently are no FDA-approved therapies for many rare epilepsies, which is precisely why new therapies targeting the rare epilepsies enjoy expedited review at FDA.

The proposal also includes other changes, like reducing coverage for non-emergency medical transportation, which is critical for people living with epilepsy who cannot drive. We already submitted [comments](#) expressing concerns when the proposal was pending at the state level, and will do so again now that it is pending at the federal level.

The Epilepsy Foundation, and several of our local affiliates and chapters, has also joined [comments](#) submitted to CMS by a group of 222 organizations that particularly highlight concerns with the closed formulary aspect of the proposal.

### **Epilepsy Foundation Urges Support for Medicare Part D Low-Income Subsidy (LIS) or Extra Help Program**

The Epilepsy Foundation strongly supports the Medicare Part D Low-Income Subsidy (LIS) or Extra Help program, which helps low-income Medicare beneficiaries afford prescription medications. More than 11 million Medicare beneficiaries rely on this program to access needed medications, including more than 6 million that are dual eligible for both Medicare and Medicaid. Unfortunately, some in Congress, as well as the Medicare Payment Advisory Commission (MedPAC), have proposed changes, including decreasing subsidies for brand medicines used by LIS and dual eligible beneficiaries in the hopes of cutting costs. If implemented, these changes would place the most vulnerable beneficiaries in the Part D program at great risk.

On October 2, 2017, the Epilepsy Foundation, and many of our local chapters and affiliates, joined hundreds of other organizations in sending to letter to members of Congress urging support for the program. Read the coalition letter [here](#).

### **Senate Committee Again Looking at Drug Prices**

On Tuesday, October 17, 2017, the Senate Committee on Health, Education, Labor and Pensions held a hearing entitled "The Cost of Prescription Drugs: How the Drug Delivery System Affects What Patients Pay." Chairman Alexander stressed the need to eventually look at all aspects of health care spending - "the 15 percent or so we spend on prescription drugs, including retail and prescription drugs administered in hospitals, and the other 85 percent of health care spending, which includes doctors' visits, surgeries, and medical devices."

During the hearing, representatives from both the generic and brand drug manufactures testified, as well as individuals representing pharmacy benefit managers (PBMs), pharmacists, and pharmaceutical distributors. The most significant agreement revolved around the need to update regulations to allow value-based payment agreements so insures and the government can pay drugmakers based on whether a treatment actually works for a patient.

This hearing was the second in a planned series of hearings to unpack the costs of medications. The first hearing was held on June 12 and was tied up in the broader health care debate about proposals to "repeal and replace" the Affordable Care Act.

The Epilepsy Foundation continues to monitor these hearings and encourage inclusion of the patient voice in discussions about the value of therapies and health care overall.

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### **State Advocacy**

### **Washington Proposes a Goldcard Program to Streamline Prior Authorizations**

Prior authorization is a process used by insurance companies that requires doctors to provide a compelling clinical reason for why a patient needs a medical treatment before the insurance company will cover that treatment.

In Washington, regulators recently began the rulemaking process to develop policies that would potentially optimize the prior authorization process for private insurers in the state through a "goldcard" program. In states like Indiana and Minnesota similar programs designate certain health care providers as "preferred providers," allowing them to bypass prior authorization requirements.

On August 16, 2017, the Epilepsy Foundation submitted [comments](#) to Mike Kreidler, Insurance Commissioner for the State of Washington, to emphasize that any Washington state Gold Card program must expand -- not limit -- access to medications and services for people with epilepsy. Again, on October 10, 2017, the Epilepsy Foundation submitted a [comment](#) to the drafted rule, urging a streamlined prior authorization process and cautioning against the potentially high administrative burden for doctors that could disincentivize participation.

### **As Pennsylvania Moves Closer to Excepting Epilepsy Medications from Monitoring Program, Michigan Looks at Expanding its Monitoring Program**

State prescription drug monitoring programs (PDMP) are intended to curb prescription drug abuse by carefully monitoring the prescribing and dispensing of Scheduled medications. The Epilepsy Foundation is opposed to the inclusion of Schedule V drugs, which include epilepsy medications, in these monitoring programs. Inclusion of Schedule V drugs can delay access to epilepsy treatments, putting individuals at risk for breakthrough seizures and related complications.

On October 18, 2017, the Pennsylvania Senate unanimously passed Senate Bill 728, which would exempt epilepsy medications from the state's PDMP. Exempting Schedule V non-opioid medications is a simple way to ensure timely access to physician-directed care while still addressing prescription drug abuse via the monitoring program. We have sent several letters to members in support of this bill and the House companion bill. Follow the issue at [advocacy.epilepsy.com/Pennsylvania](http://advocacy.epilepsy.com/Pennsylvania).

In Michigan, the Epilepsy Foundation is closely monitoring Senate Bill 166, which would require physicians to consult the state's prescription drug monitoring program when prescribing Schedule II-V drugs. The inclusion of Schedule V drugs would limit access to some epilepsy medications, and we have urged legislators to amend the bill to remove the requirements that would affect people living with epilepsy. We have sent several letters regarding this issue, the latest [letter](#) sent on September 26, 2017.

Follow this issue across all of the states and learn more at [advocacy.epilepsy.com/PDMP](http://advocacy.epilepsy.com/PDMP).

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