



Highlights from the Hill

November 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](#).

National Advocacy

November is National Epilepsy Awareness Month

November is National Epilepsy Awareness Month! You can participate in the #MyShotAtEpilepsy campaign on social media to raise awareness and funds for a cure. You can

also raise awareness about SUDEP and reducing its risk with the #AimForZero campaign. There are [so many ways to get involved](#).

Another way to participate this November is by sharing your health care story with us! Are you on an ACA Marketplace (exchange) plan? Do you rely on Medicaid or Medicare? Your story can make a difference and help educate policymakers in the ongoing health care debate. Let your voice be heard by filling out the form: bit.ly/storyEF.

Read stories of other people living with epilepsy at advocacy.epilepsy.com/efa/advocacymatters.

UPDATE: ACA and the Congressional Health Care Debate

Earlier this fall, Senators Alexander and Murray, leaders of the Senate Committee on Health, Education, Labor and Pensions (HELP), announced a bipartisan agreement on a bill to stabilize the Affordable Care Act (ACA) Marketplace. The proposed legislation, the Bipartisan Health Care Stabilization Act of 2017, would extend cost-sharing reduction (CSR) payments, and includes other mechanisms of stabilization. CSRs help lower-income individuals and families (who make up to 250% of the federal poverty line) cover out-of-pocket health care costs like deductibles and co-pays for plans offered in the ACA Marketplace. The proposal would also preserve and support key protections for individuals with pre-existing conditions. Since being introduced, [the bill has garnered support from over 200 groups](#), including the Epilepsy Foundation.

The Bipartisan Health Care Stabilization Act of 2017 was scored in late October by the nonpartisan Congressional Budget Office (CBO). CBO estimates that enacting this piece of legislation would reduce the federal deficit by \$3.8 billion over a ten year period. On October 26, 2017, after the CBO published a score of the Alexander-Murray bill, we joined a [statement](#) with many others in the patient community continuing to express support for the bill and encouraging other legislators to join as sponsors.

Further, on October 25, 2017, the Epilepsy Foundation sent [letters](#) to Sens. Alexander and Murray, and additional cosponsors, in support of the bipartisan effort and the bill. We believe this bill is an encouraging move towards bipartisanship and will continue to advocate for its passage.

Continue to follow the debate and learn more about the Affordable Care Act at advocacy.epilepsy.com/ACA.

UPDATE: Massachusetts Medicaid Waiver Amendment

The proposal to amend Massachusetts's Medicaid (MassHealth) waiver is currently pending at the Centers for Medicare and Medicaid Services (CMS). If approved, this waiver could have a significant impact on access to treatments, especially innovative medications, for those in Massachusetts Medicaid and beyond. This waiver has the potential to set a dangerous precedent for Medicaid programs across the country. 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.

The Epilepsy Foundation is particularly concerned about aspects of the proposal that would limit access to medications. One proposal would create a closed formulary that would require coverage of just one drug per class, while another proposal would limit access to innovative new therapies approved by the FDA via expedited pathways by subjecting them to additional efficacy reviews. 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 rare and severe forms of epilepsy.

The Epilepsy Foundation submitted several comments to CMS, including a [comment](#) with the Epilepsy Foundation of New England and a [comment](#) joined by ten epilepsy groups.

Read more about the MassHealth Waiver at advocacy.epilepsy.com/MedicaidWaivers.

House Passes Reauthorization of the Children's Health Insurance Program (CHIP)

On November 3, 2017, the House passed H.R. 3922, the Championing Healthy Kids Act, by a vote of 242-174. The Championing Healthy Kids Act includes a 5-year funding extension for 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. More than one million members of the epilepsy community depend on CHIP or Medicaid to access high-quality, affordable health care.

CHIP has bipartisan support, but the vote was largely along party lines. Opposition to the bill revolved around provisions that would cut funding to the prevention and public health fund in order to pay for these funding extensions and public health programs. The bill still needs to be considered by the full Senate before heading to the president for enactment. The Epilepsy Foundation will continue to support the reauthorization of CHIP.

Read more about CHIP and follow our efforts at advocacy.epilepsy.com/CHIP.

Protecting Patient Access to Emergency Medications Act of 2017 Sent to President Trump

The Protecting Patient Access to Emergency Medications Act of 2017, H.R. 304, passed the U.S. House of Representative by a vote of 404-0 in early January 2017. On October 24, 2017, the bill passed the Senate by unanimous consent. On November 7, 2017, the bill was presented to President Trump for his signature.

The Epilepsy Foundation has supported this bill since it was first introduced in the last Congress. The bill would make changes to the Drug Enforcement Administration's registration process for emergency medical services (EMS) agencies and clarify that they can administer certain approved medications to their patients. This bill would directly benefit many people in the epilepsy community. There is a demonstrated clinical need for administering controlled substance medications, such as those to treat active seizures, during an emergency. Delaying

immediate treatment by first responders with a readily available emergency medication can be life-threatening. Prolonged, cluster, or status seizures may cause serious injury and even death.

Epilepsy Foundation Participates in ADA Civil Rights Roundtable

On November 2, 2017, Cherree Sanders, manager of the Jeanne Carpenter Epilepsy Legal Defense Fund, attended a civil rights roundtable discussion hosted by the U.S. Attorney's Office for the Eastern District of Virginia and led by Steven Gordon, Assistant U.S. Attorney and Civil Rights Enforcement Coordinator. The roundtable focused on the Americans with Disabilities Act (ADA) in state and local corrections, law enforcement, and judicial settings. The Epilepsy Foundation was one of several disability rights organizations in attendance. Title II of the ADA covers state and local government entities, including law enforcement agencies, courts, and jails and correctional facilities. People living with epilepsy are protected by the ADA and appropriate accommodations should be made in these settings.

During the roundtable, U.S. Attorney Gordon noted that the law requires correctional settings to have an on-site ADA coordinator who is publicly available. During some investigations, it has been found that an ADA coordinator is either not available or is not fully aware of the requirements of the ADA. The presentation highlighted that one of the challenges to advocating for people with disabilities in these settings are attitudinal barriers that include unfamiliarity with the ADA and the perspective that reasonable accommodations to inmates are sometimes viewed as "special privileges."

Attendees were invited to share concerns they hear from the communities they represent. Some concerns shared by the Epilepsy Foundation and other disability rights groups included failure to provide access to medications, failure to provide reasonable accommodations, penalties for behaviors associated with seizures and other disabilities (e.g., placement in solitary confinement or conduct penalties), and the need for ADA training in these settings, as well as sensitivity/awareness training and de-escalation methods when interacting with people with disabilities.

Learn more about the Jeanne Carpenter Epilepsy Legal Defense Fund at www.epilepsy.com/living-epilepsy/legal-help.

Follow the Epilepsy Foundation's disability advocacy efforts at advocacy.epilepsy.com/ADA

Epilepsy Foundation Advocates for Justice Department Appropriations Amendment on Medical Cannabis

The Epilepsy Foundation joined several other patient groups in sending a [letter](#) to the Senate Committee on Appropriations urging them to support an amendment in the Commerce, Justice, Science and Related Agencies Appropriations bill that would protect access to medical cannabis pursuant to state laws.

The amendment would prohibit the Justice Department from using funds to prevent states from implementing their own state laws that authorize the use, distribution, possession, or cultivation of medical cannabis.

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 continue to support lifting federal barriers to research on cannabis and CBD and support access to these potential therapies, through state-regulated programs, for individuals living with intractable epilepsy and when other treatment options have failed, in consultation with the treating physician.

Read more about medical cannabis advocacy at advocacy.epilepsy.com/medical-cannabis.

Epilepsy Foundation Supports the Orphan Drug Tax Credit

On November 8, 2017, the Epilepsy Foundation, along with over 200 patient organizations, sent a [letter](#) to House leadership in support of the Orphan Drug Tax Credit (ODTC). The *Tax Cuts and Jobs Act* would repeal the ODTC.

The Orphan Drug Tax Credit is one of the most important incentives for companies to develop therapies for individuals with rare diseases. The ODTC allows drug manufacturers to claim a tax credit of 50 percent of the qualified costs of clinical research and drug testing of orphan drugs (drugs for diseases affecting 200,000 Americans or fewer). In the decade before the Orphan Drug Act, which included the ODTC, only ten medicines were developed by industry for rare diseases. However, since passage of that legislation, more than 3,500 potential treatments have been designated as an orphan drug, and more than 500 orphan therapies have been approved by the Food and Drug Administration. This is a direct result of the incentives enacted in the Orphan Drug Act, including the tax credit.

Enrollment for the ACA and Medicare Part D is Open

Enrollment for the 2018 Health Insurance Marketplace began on November 1, 2017. The last day to enroll in the individual market for coverage starting in January 2018 is December 15, 2017.

[There are five different ways to enroll and many different plan options.](#) Please visit HealthCare.gov to learn more and if you have any questions you can call the 24-hour Marketplace Call Center at 1-800-318-2596.

Medicare Part D enrollment began on October 15, 2017. To receive drug coverage starting in January 2018, use the [Medicare Plan Finder](#) and enroll by December 7, 2017. You can read more about Medicare Part D [here](#). If you have any questions you can call 1-800-MEDICARE (1-800-633-4227).

The end of the year is fast approaching, which means the 2018 state legislative season will be here soon. The Epilepsy Foundation is ready to lead advocacy efforts [to ensure access to quality care](#) and in support of our [policy priorities](#).

We want to make sure you are well informed about what is happening right in your backyard so you can make your voice heard. Curious to see what the Epilepsy Foundation has been working on in your home state? You can view our state advocacy efforts [here](#).

We strongly encourage you to update your contact information, including your home address, so that we can send targeted alerts based on your state and congressional district to you. Please do so by completing the form [here](#) – which will only be used for our Speak Up, Speak Out advocacy network.

UPDATE: Access to Medical Cannabis in Michigan

In August 2017, members of the Michigan Medical Marijuana Licensing Board were considering a proposal to shut down all medical cannabis dispensaries in the state while they implemented a new licensing process. On August 30, 2017, the Epilepsy Foundation wrote a [letter](#) to the Michigan Medical Marijuana Licensing Board, urging members to ensure that access to medical cannabis is not disrupted during the transition to new licensing regulations in the coming year. In October 2017, bills were introduced in Michigan to help ensure current access to medical cannabis is sustained while the new regulations are being developed and implemented. The Epilepsy Foundation sent a [letter](#) urging the Michigan State Senate and State House to support this legislation when it was introduced in October.

On November 1, 2017, the Michigan state Department of Licensing and Regulatory Affairs approved an emergency rule that will enable existing dispensaries to stay open while they go through the licensing process, ensuring access to medical cannabis during the transition. Patient input, especially from the Epilepsy Foundation and our Michigan affiliate, Epilepsy Foundation Michigan, played a large role in the decision.

Learn more about our advocacy as it relates to medical cannabis at advocacy.epilepsy.com/medical-cannabis.

Email us at TSU@efa.org

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