Highlights from the Hill
November 2018

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National Advocacy

November is National Epilepsy Awareness Month

November is National Epilepsy Awareness Month! This year during National Epilepsy Awareness Month, the Epilepsy Foundation is launching a nation-wide campaign, “Let’s Use Our Brains to End Epilepsy.” The multi-year campaign focuses on the brain as the source of seizures but also as the source of the solution to End Epilepsy. We are challenging the nation to think differently about epilepsy and seizures and hope to bring more understanding and awareness to the public.

Learn how to participate here and find out more about the End Epilepsy campaign at EndEpilepsy.org.

2018 Midterm Election Results

As a result of the midterm elections and beginning in January, the Democratic Party will take the majority in the House of Representatives and the Republican Party will maintain its majority in the Senate. There will subsequently be significant changes in leadership, committee leadership and committee membership in the House, as well as some changes in the Senate. As we prepare to advocate for our policy priorities in the 116th Congress, we will be monitoring changes to these key committees: Senate Appropriations, Finance, and Health, Education, Labor and Pensions (HELP) Committees and the House Appropriations, Ways and Means, Energy and Commerce, and Education and Workforce Committees. The Epilepsy Foundation remains committed to working on issues important to the epilepsy community with all Members of Congress.

Learn more about our policy priorities at advocacy.epilepsy.com/policy-priorities.

Epilepsy Foundation Speaks Out on New Waiver Guidance from CMS

In late October, the Centers for Medicare and Medicaid Services (CMS) issued a new guidance regarding Section 1332 waivers under the Affordable Care Act (ACA). Currently, these waivers give states the authority to pursue innovative strategies for providing their residents with access to high quality, affordable health insurance while retaining the basic protections of the ACA and maintaining budget neutrality.

The Administration’s newly issued guidance allows states to promote health plans that do not require the same level of coverage or consumer protections set forth by the ACA. States will be able to make short-term and association health plans more widely available and offer subsidies for people to buy these plans. However, these plans have less comprehensive coverage and can exclude or charge people with pre-existing conditions more. In addition, state legislatures will no longer have to approve the waiver plans; that power will rest only with the governor.

The Epilepsy Foundation signed onto a statement with more than 25 national patient organizations expressing deep concern over the new guidance. We firmly support access to quality health care that is affordable and comprehensive, and that meets the needs of individuals with serious and chronic health conditions. We are particularly concerned about the effect the new guidance may have on individuals with pre-existing conditions and the stability of the Marketplace.

Read more about our efforts to protect patients with pre-existing conditions at advocacy.epilepsy.com/ACA.
Reminder: Open Enrollment for Medicare and Marketplace Plans

Open enrollment for Medicare and Marketplace plans is underway. People seeking to buy or change their Medicare or Marketplace plan must do so during open enrollment unless a specific exception occurs like moving out of state or having a baby. It is very important to use this time to compare your coverage choices and find the plan that best meets your health care and prescription drug needs. Each year, plans make changes to benefits and costs, and new plans are available, so your current plan may or may not be the best plan for you in 2019.

The annual open enrollment period for Medicare prescription drug coverage (part D) and Medicare Advantage began on **October 15, 2018 and will run through December 7, 2018** for coverage beginning January 1, 2019. Visit [medicare.gov](http://medicare.gov) or call 1-800-MEDICARE (1-800-633-4227) to learn more.

The open enrollment period for the Health Insurance Marketplace began **November 1, 2018 and will run through December 15, 2018** for coverage beginning January 1, 2019. Learn more about your options at [healthcare.gov](http://healthcare.gov) or 1-800-318-2596 (TTY: 855-889-4325). Individuals may be eligible for premium tax credits that will help make coverage more affordable. Please note that the healthcare.gov website is scheduled to be down every Sunday during open enrollment from 12 a.m. until 12 p.m. except December 9, 2018 due to maintenance—so consumers should plan to enroll around those time constraints.

Learn more about open enrollment and find helpful resources at [advocacy.epilepsy.com/openenrollment](http://advocacy.epilepsy.com/openenrollment).

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**STATE ADVOCACY**

2018 Ballot Initiatives in the States: Medicaid Expansion and Cannabis

This past Election Day, voters across the U.S. had the opportunity to decide on different issues on the ballot. These ballot initiatives have wide-ranging effects on the state in which you live.

Medicaid expansion — which the Foundation supports — was on the ballot in four states. Three of those states – Idaho, Nebraska, and Utah — approved those measures and will proceed to expand Medicaid. The Medicaid expansion in these states means approximately more than 300,000 Americans will receive access to affordable, quality health care. The fourth state, Montana, had already expanded Medicaid—but voters rejected continuing to fund it past June 2019. Advocates will now turn to Montana’s legislature to try and provide the funding to maintain coverage for the expansion population.

In addition, several Governor race outcomes may have an impact on Medicaid expansion. Recently elected Governors in Wisconsin and Kansas have pledged support for Medicaid expansion and the Governor-elect of Maine supports implementation of the Medicaid expansion that was passed in 2017 through a ballot initiative.

In four states — Michigan, Missouri, North Dakota, and Utah — voters decided whether to expand the legalization of cannabis. Proposal 1 in Michigan passed and fully legalizes recreational cannabis in the state for adults age 21 and older, while recreational use in North Dakota did not pass. Missouri had three cannabis ballot measures and voters approved one of them — Amendment 2 — which gives individuals with qualifying conditions including epilepsy access to medical cannabis and taxes sales at 4 percent. Utah’s Proposition 2 passed, which allows patients with certain
qualifying conditions including epilepsy access to 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 support safe, legal access to medical cannabis and CBD if a patient and their health care team feel that the potential benefits of medical cannabis or CBD for uncontrolled epilepsy outweigh the risks.

A Pathway for Epidiolex® in the States

A pathway has been created for Epidiolex®, the first U.S. Food and Drug Administration (FDA) approved treatment derived from cannabidiol (CBD), in every state except Texas. Epidiolex® was federally reclassified as a Schedule V substance by the Drug Enforcement Administration (DEA) on September 27, 2018. We anticipate Epidiolex® becoming available in Texas by the end of the year.

Read the letters and stay apprised of our advocacy efforts on FDA-approved therapies derived from CBD at advocacy.epilepsy.com/statefdapathway.

Epilepsy Foundation Urges Open Access to Epilepsy Medications in Wisconsin

The Epilepsy Foundation and the Epilepsy Foundation Heart of Wisconsin are urging the Medicaid Prior Authorization Advisory Committee in Wisconsin 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 testimony for the Advisory Committee here.

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

Epilepsy Foundation of Michigan Warns Consumers of Copay Accumulator Policies

On November 8, 2018, the Michigan Coalition for Affordable Prescriptions, which includes the Epilepsy Foundation of Michigan, put out a press release warning consumers about an insurance policy change from a number of major health insurers regarding manufacturer copay coupons. Manufacturer coupons help defray the cost of many prescription medications. Typically, the copay assistance would apply toward an individual's deductible or out-of-pocket maximum. The new policy change would not allow the coupon to count toward the out-of-pocket maximum, which means that individuals and their families may face steep increases in their out-of-pocket costs.

Learn more about our efforts on copay assistance programs at advocacy.epilepsy.com/copay.

D.C. City Council Passes Legislation to Restrict Short-Term Health Plans

On November 13, 2018, the D.C. City Council passed legislation that would restrict the sale of second-rate, short-term health insurance plans. These so-called “short-term limited duration plans” lack many of the important consumer protections set forth by the Affordable Care Act (ACA)—making them insufficient, especially for those living with epilepsy or any chronic, complex diseases. The Epilepsy Foundation and the Epilepsy Foundation of Metropolitan Washington supported the legislation, which would strengthen important protections for those with pre-existing conditions and make sure that individuals cannot purchase more than one of these substandard plans each year. We applaud the D.C. City Council’s move to protect Washingtonians’ health care and urge Mayor Bowser to sign the legislation.
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.

Email us at TSU@efa.org

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