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National Advocacy

**Epilepsy Foundation Mobilizes Opposition to CMS’s Proposed Rule that Would Weaken Medicare Part D’s Six Protected Classes**

In late 2018, the Centers for Medicare and Medicaid Services (CMS) proposed a new rule that threatens to weaken Medicare Part D’s Six Protected Classes policy. The policy was designed to ensure that Medicare Part D beneficiaries living with serious conditions — like epilepsy, HIV/AIDS, mental illness, cancer and organ transplants — have reliable and affordable access to life-changing and life-saving medications. The proposed rule would allow plans to exclude protected class drugs, such as anticonvulsants, from their formularies in certain instances, as well as allow for greater use of step therapy and prior authorization including for people who are currently stable on their medication.

Since CMS released the proposed rule, the Foundation has embarked on a multi-faceted and targeted advocacy effort to voice opposition. In addition to submitting its own comments, the Foundation helped organize group comments to CMS from more than 30 epilepsy organizations through the Epilepsy Leadership Council and worked with coalition partners and signed on to group comments organized by the American Cancer Society Cancer Action Network, the Consortium for Citizens with Disabilities, the Partnership for
Part D Access, and MAPRx. On January 30, 2019, the Foundation’s President and CEO Phil Gattone joined other impacted advocacy organizations, including AIDS United, on a media roundtable expressing collective concerns with the proposed Medicare Part D changes. Additionally, the Foundation is participating in a targeted print, radio, and television ad campaign to spread awareness about the Six Protected Classes and the negative impact the proposed rule will have on Medicare beneficiaries.

We are sincerely grateful for all the grassroots advocates who took action and submitted their own comments to CMS during the public comment period, resulting in more than 870 comments from the epilepsy community! With the comment period to the Administration closed, now is the time to contact your federal legislators. Congress has played a critical role in reminding the Administration about the policy’s purpose and getting it to pull back previous dangerous proposals that would have harmed beneficiary access. **Tell your Members of Congress to stand up alongside you and tell the Administration to stop these changes!**

Read all of the comments and learn more about Medicare’s six protected classes at [advocacy.epilepsy.com/ProtectedClasses](http://advocacy.epilepsy.com/ProtectedClasses).

**Foundation Endorses the Protecting Americans with Pre-existing Conditions Act**

On February 6, 2019, Representatives Kuster (NH-02), Beyer (VA-08) and Courtney (CT-02) introduced the *Protecting Americans with Pre-Existing Conditions Act* (H.R. 986). On February 13, 2019, Senators Warner (VA), Cardin (MD), Shaheen (NH) and Baldwin (WI) introduced identical legislation, S. 466, in the Senate. The legislation would revoke the Section 1332 guidance released by the Centers for Medicare and Medicare Services (CMS) in late October 2018. The guidance relaxes important guardrails and weakens protections for individuals with pre-existing conditions. The Foundation, along with multiple national patient organizations, has endorsed this important legislation. Read the press release [here](http://here).

Read our comment letter to CMS and learn more about our efforts to protect individuals with pre-existing conditions at [advocacy.epilepsy.com/ACA](http://advocacy.epilepsy.com/ACA).

**Foundation Weighs in on Affordable Care Act Proposed Regulation**

On February 19, 2019, the I Am Essential coalition, co-led by the Foundation, *submitted comments signed by over 85 patient and consumer groups*, to the Administration on an annual regulation governing Affordable Care Act (ACA) plans, the *Notice of Benefit and Payment Parameters*. The Foundation also joined another coalition of national patient advocacy organizations and the Consortium for Citizens with Disabilities (CCD) in submitting comment letters. This year, the Administration proposed a number of concerning proposals, including allowing mid-year formulary changes, endorsing copay accumulator programs for brand name medications with generic equivalents, and disallowing any out-of-pocket spending on brand name drugs to count toward out-of-pocket maximums if a generic equivalent is available. The proposed rule made other changes concerning to health care access, including increasing out-of-pocket maximums.
Read all of the comments and learn more about the Affordable Care Act at advocacy.epilepsy.com/ACA.

2019 Spending Bill Completed, Averting Government Shutdown

The Labor-Health and Human Services spending bill, which funds departments and agencies such as the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) was signed into law in 2018, but funding for several other important departments remained incomplete until very recently. With a few hours to spare, on February 15, 2019, Congress passed and the President signed into law a bill that funds the remainder of the federal government through September 30, 2019. This included a $269 million increase for the Food and Drug Administration (FDA).

Now, the process for the 2020 federal budget begins. The President is expected to release his budget blueprint in mid-March and then congressional appropriations committees will start their work. The Foundation will be actively advocating for several budget items including the CDC’s Chronic Disease Prevention and Health Promotion’s funding for epilepsy.

Find out more on federal funding for epilepsy research and programs at advocacy.epilepsy.com/federal-funding-for-epilepsy.

On January 24, 2019, the Epilepsy Foundation of Delaware hosted their fifth annual legislative luncheon at the state capitol!

STATE ADVOCACY

Safeguarding Access to Medications

For the majority of people living with epilepsy, medications are the most common and cost-effective treatment for controlling and/or reducing seizures. Epilepsy medications are not interchangeable, and treatment of epilepsy is highly individualized - there is no "one size fits all" treatment option. Maintaining seizure control with minimal side effects requires
careful evaluation and monitoring by physicians and their patients. To change, limit, or deny access to medications could be extremely dangerous. During the 2019 state legislative session, we are monitoring legislation that would have a significant impact for the epilepsy community on accessing and affording prescription medications.

Medication formulary changes that interrupt continuity of care can be extremely dangerous and lead to breakthrough seizures and related complications, including death. Bills that would improve continuity of care by limiting insurers’ ability to change formularies mid-year and related continuity of care protections have been introduced in Connecticut, Iowa, Indiana, Maryland, Minnesota, New York and Texas.

Learn more about continuity of care and mid-year formulary changes at [advocacy.epilepsy.com/formulary-changes](http://advocacy.epilepsy.com/formulary-changes).

Step therapy, or “fail first,” is a process used by insurance companies to require enrollees to try and fail on other medications – usually older and cheaper medications – preferred by their insurers before receiving the medication their provider originally prescribed and that is most effective for them. Currently, bills that would require a streamlined appeals or exception process with step therapy override protocols have been introduced in the following states: Connecticut, Florida, Iowa, Kansas, Minnesota, Missouri, Oklahoma, Virginia, Washington, and Wisconsin.

**Spotlight on Oklahoma**

Read an op-ed by Jenniafer Walters, Executive Director of the Epilepsy Foundation of Oklahoma, on this issue [here](http://example.com).

Learn more about step therapy at [advocacy.epilepsy.com/steptherapy](http://advocacy.epilepsy.com/steptherapy).

Across the country, some prescription drug manufacturers offer copay assistance for specialty drugs to individuals who may be struggling to afford their medications for various reasons. While other strategies to help make medications more affordable overall are being pursued, copayment assistance programs currently play a critical role in ensuring individuals can gain and maintain seizure control while keeping costs low.

During this session, we are supporting legislation that would require that copayments paid in any form, including through a copay assistance program, count toward an individual's deductible or out-of-pocket maximum so that more financial burden is not placed on the individual. We are supporting similar legislation in Arizona, Connecticut, Indiana, Oregon, Virginia, and West Virginia.

Read more about copay assistance programs at [advocacy.epilepsy.com/copay](http://advocacy.epilepsy.com/copay).
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.

Stay up to date with the legislation in your state by visiting advocacy.epilepsy.com/states.

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