



December 17, 2019

The Honorable Nancy Pelosi  
Speaker of the House  
U.S. House of Representatives  
Washington, D.C. 20515

The Honorable Mitch McConnell  
Majority Leader  
U.S. Senate  
Washington, D.C. 20510

The Honorable Kevin McCarthy  
Minority Leader  
U.S. House of Representatives  
Washington, D.C. 20515

The Honorable Chuck Schumer  
Minority Leader  
U.S. Senate  
Washington, D.C. 20510

Dear Speaker Pelosi, Majority Leader McConnell, Minority Leader McCarthy, and Minority Leader Schumer:

On behalf of the Epilepsy Foundation, and the 3.4 million Americans living with epilepsy and seizures, we write to thank Congress for its efforts so far in seeking to address the high cost of prescription drugs and other challenges people face accessing needed medications, including attaching the CREATES Act to the year-end appropriations bill. Various packages and standalone bills have been introduced and advanced in Congress and the Administration has expressed support for action, but more needs to be done. We stand at an unprecedented juncture where we can make a difference in the lives of millions of Americans. We urge Congress to take this opportunity and pass bipartisan solutions before the end of the year to address the high cost of prescription drugs, resulting high out-of-pocket costs and other challenges facing people with epilepsy and other acute and chronic health conditions.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of more than three million Americans with epilepsy and seizures. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime. For the majority of people living with epilepsy, anti-seizure medications are the most common and most cost-effective treatment for controlling and/or reducing seizures.

Delays and barriers to accessing needed anti-seizure medications stem from many factors, including insurance practices like prior authorization and step therapy and high drug costs, and have serious consequences. Twenty-one percent of adults with epilepsy reported not being able

to afford prescription medications within the last year.<sup>1</sup> Delaying access to the anti-seizure medication(s) that work(s) for a particular person puts him/her at risk for breakthrough seizures and related complications including injury, disability, loss of mobility or employment, and even death. Mortality rates among people with epilepsy are three times higher and sudden death rates are twenty times higher than rates for the general population. When people with epilepsy are not on the anti-seizure medication that works for them, it also causes higher costs for the healthcare system. A review of studies has shown that direct, epilepsy-related medical costs associated with uncontrolled epilepsy are 2 to 10 times higher than costs associated with controlled epilepsy.<sup>2</sup>

Congress has taken significant action this year to address the high cost of prescription drugs and other access challenges, including the Lower Health Care Costs Act, Prescription Drug Pricing Reduction Act, the Elijah Cummings Lower Drug Costs Now Act (H.R. 3), and many other bills that have been passed out of relevant committees. There are also standalone bills such as the Safe Step Act (H.R. 2279/S. 2546). The Epilepsy Foundation believes bipartisan efforts are both feasible and necessary and in line with our [principles and positions on Access to Prescription Medications](#). We are pleased to see the CREATES Act included in the year-end package, but we urge Congress to continue to work on a bipartisan package that contains the following bipartisan provisions:

- A cap on out-of-pocket costs in Medicare Part D, including a way to smooth costs throughout the year;
- Restructuring and simplifying the Medicare Part D benefit, finally eliminating the donut hole and including manufacturer liability in the initial and catastrophic phases;
- Reducing beneficiary cost sharing, including reducing beneficiary liability in the initial coverage phase and passing through rebates to beneficiaries at the point of sale;
- Increasing transparency throughout the supply chain;
- Addressing other anticompetitive practices, including abuses of the citizen petition process, “pay for delay” agreements, and other delays generics coming to market; and
- Addressing step therapy by including the Safe Step Act.

We also encourage Congress to address the significant rise in the catastrophic limit that will occur on January 1, 2020. This scheduled increase has not been included in any of the major legislative packages, and one of the many reasons why action is necessary before the end of the year.

Throughout the 116<sup>th</sup> Congress, members have shown bipartisan support for each of the provisions outlined above, including through bipartisan votes out of relevant committees. The time for Congress to act is now.

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<sup>1</sup> David J. Thurman et al., *Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013*, 55 *EPILEPSY BEHAV* 184-88 (2015). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5317396/>

<sup>2</sup> *Ibid.*

The Epilepsy Foundation thanks you for your leadership and urges you to work together to move forward and enact a bipartisan proposal to address high drug costs and other challenges accessing needed medications. Please do not hesitate to contact me at [lweidner@efa.org](mailto:lweidner@efa.org) or 301-918-3766 with any questions.

Sincerely,

A handwritten signature in black ink, appearing to read 'Laura Weidner', with a long horizontal stroke extending to the right.

Laura Weidner, Esq.  
Vice President, Government Relations & Advocacy  
Epilepsy Foundation

cc:

Senate Finance Committee Chairman Charles E. Grassley  
Senate Finance Committee Ranking Member Ron Wyden  
Senate HELP Committee Chairman Lamar Alexander  
Senate HELP Committee Ranking Member Patty Murray  
House Majority Leader Steny H. Hoyer  
House Energy and Commerce Committee Chairman Frank Pallone, Jr.  
House Energy and Commerce Committee Ranking Member Greg Walden  
House Ways and Means Committee Chairman Richard E. Neal  
House Ways and Means Committee Ranking Member Kevin Brady