



July 6, 2020

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

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

Dear Majority Leader McConnell and Minority Leader Schumer:

As Congress continues deliberating additional legislation to respond to the novel Coronavirus (COVID-19) pandemic, the Epilepsy Foundation writes to urge Congress to ensure the needs of individuals with complex, chronic conditions, like epilepsy, are adequately addressed. Specifically, Congress should pass provisions that would re-open the enrollment period in the health insurance marketplace nationwide; expand paid leave; ensure all adults with disabilities are eligible for economic impact payments, suspend step therapy protocols; and increase funding for state Medicaid programs and target additional support for home and community-based services.

The Epilepsy Foundation is the leading national voluntary health organization that speaks of behalf of the approximately 3.4 million individuals living with epilepsy and seizures in the United States. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition characterized by seizures, which are sudden surges of electrical activity in the brain, that affects a variety of mental and physical functions. Epilepsy is a spectrum disease with a wide range of seizure types and control varying from person-to-person.

The COVID-19 pandemic is impacting people with the epilepsies, as well as others with serious and chronic conditions and disabilities in many ways, especially as the need to social distance creates new challenges when it comes to accessing health care and vital forms of support. The Epilepsy Foundation is encouraged by legislative efforts so far that have provided some relief to the American people and economy, but we remain acutely aware that there is still much more support needed to ensure that the needs of individuals living with chronic conditions and disabilities are met and their rights protected.

Access to affordable, comprehensive, quality health coverage and care including necessary treatments is critical for people with epilepsy to maintain their quality of life and hopefully achieve seizure freedom. In order to ensure that individuals have access to health insurance to receive the care necessary to treat epilepsy and seizures, Congress should direct the administration to immediately initiate a 60-day special enrollment period for Marketplace plans nationwide. Further, more than one million people with epilepsy rely on Medicaid—making it an essential health coverage program for our population, particularly during such challenging times as the COVID-19 pandemic. We urge Congress to increase federal support for state Medicaid programs from 6.2 to 14 percent and continue to couple it with a maintenance of effort provision, as well as provide targeted support for home and community-based services.

Our mission is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. **Please learn more about our advocacy work at [epilepsy.com/advocacy](https://www.epilepsy.com/advocacy).**



We also urge Congress to institute guardrails and protections on the use of step therapy protocols in Medicare Advantage, Medicare Part D Plans, Medicaid Managed Care, and ERISA health plans during and until at least one year after the public health crisis. 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. 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. The Epilepsy Foundation believes that treating providers, not insurance companies, are best suited to decide which medication is appropriate for an individual. In turn, by ensuring that individuals are on the right treatment option for them, we can help alleviate stress in an already taxed health care system and free up resources to fight the COVID-19 pandemic.

Currently, paid leave only provides support to those with children whose school or child care are closed due to the pandemic. We appreciate this initial step but urge that paid sick days and paid leave be expanded to include caregivers who cannot work because they are caring for an adult with a disability or aging family member whose program has closed or care worker is sick. We also urge that paid leave provisions protect people working for employers of all sizes.

Finally, we urge Congress to ensure that adults who are claimed as a dependent are eligible for economic impact payments. Due to the definition of dependent in the CARES Act, adults claimed as dependents (who are nearly always people with disabilities) are ineligible for \$1,200 individual payments while their families are also ineligible for the \$500 dependent credit. We urge you to include this technical fix in the next package to ensure that these families are eligible for at least the \$500 dependent payment.

We look forward to engaging with you on these important provisions to ensure that individuals with complex, chronic conditions and disabilities, such as epilepsy, are protected in the forthcoming legislation. Please contact Rachel Patterson, Senior Director, Government Relations & Advocacy, at rpatterson@efa.org with questions or concerns.

Sincerely,

A handwritten signature in black ink, appearing to read "Laura Weidner".

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

A handwritten signature in black ink, appearing to read "Laura S. Thrall".

Laura Thrall
President & CEO
Epilepsy Foundation