July 6, 2020

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

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

Dear Speaker Pelosi and Minority Leader McCarthy:

On behalf of the Epilepsy Foundation, we write to applaud your leadership in passing legislation to support the American people and economy through the novel Coronavirus (COVID-19) pandemic. While there is still work to be done to ensure that individuals living with chronic conditions and disabilities, like epilepsy, are protected during COVID-19 pandemic, many provisions included in the House-passed HEROES Act are critical to ensuring that individuals receive the care and support they need.

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. We were particularly heartened to see and thank you for including the following provisions in the HEROES Act that will preserve access to care in these unprecedented times:

- Directing the administration to initiate a 60-day special enrollment period for Marketplace plans nationwide;
- Expanding paid leave by ensuring paid sick days and provisions include caregivers who cannot work because they are caring for an adult with a disability or an aging family member;
- Ensuring that adults with disabilities who are claimed as dependents are eligible for Economic Impact Payments; and
- Increasing federal support for state Medicaid programs as well as providing targeted support for home and community-based services.

The Epilepsy Foundation applauds these provisions in the HEROES Act, and urges that they remain in the final negotiated COVID-19 package to ensure that Americans living with chronic conditions and disabilities, like epilepsy, are protected. While not included in the HEROES Act, in the negotiated package, we 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. 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.

Thank you for your leadership and the Epilepsy Foundation looks forward to continuing to work with you. Please contact Rachel Patterson, Senior Director, Government Relations & Advocacy at rpatterson@efa.org with questions or concerns.

Sincerely,

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

Laura Thrall
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