



October 17, 2018

The Honorable Tom Wolf
508 Main Capitol Building
Harrisburg, PA 17120

Dear Governor Wolf:

On behalf of the Epilepsy Foundation and our local affiliate, Epilepsy Foundation Eastern Pennsylvania, we write to thank you for your efforts to quickly reschedule Epidiolex in the state to ensure Pennsylvania patients have timely access to this new and innovative therapy.

On June 25, 2018, the FDA approved Epidiolex, a medication derived from cannabis for the treatment of two rare epilepsy conditions known as Dravet and Lennox-Gastaut (LGS) syndromes in individuals 2 years of age or older. There are ongoing clinical trials to assess the effectiveness of Epidiolex for Tuberous Sclerosis Complex (TSC), another rare epilepsy syndrome. On September 27, 2018, the DEA designated Epidiolex as Schedule V. This new treatment option represents hope for individuals living with rare and catastrophic epilepsy conditions. Your actions have ensured that people living with epilepsy will have immediate access to physician-directed care in Pennsylvania.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the at least 3.4 million Americans with epilepsy and seizures. The local affiliate, Epilepsy Foundation Eastern Pennsylvania, advocates and provides services for the approximately 133,000 individuals living with epilepsy throughout the state. Collectively, 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 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. There is no "one size fits all" treatment for epilepsy, and about a third of people living with epilepsy suffer from uncontrollable or intractable seizures, with many more living with significant side effects, despite available treatments. Uncontrolled seizures can lead to accident, injury, increased hospitalization costs, and early death.

Dravet syndrome is a rare and catastrophic form of intractable epilepsy that begins in infancy and is highly treatment-resistant. It is a debilitating, life-long condition characterized by frequent and prolonged seizures, poor seizure control, and developmental delays, as well as an increased risk of premature death including sudden unexpected death in epilepsy (SUDEP). Epidiolex is the first ever FDA-approved treatment for Dravet and represents hope for individuals living with Dravet syndrome who continue to have uncontrolled seizures and other medical needs throughout their lifetime.



Lennox-Gastaut syndrome is a rare and often debilitating form of childhood-onset epilepsy that is highly treatment-resistant. It is characterized by multiple seizure types, and moderate to severe cognitive impairment. Individuals living with LGS experience an increased risk of serious injury because of frequent falls associated with uncontrolled seizures. Despite other FDA-approved treatments for LGS, many individuals living with this rare epilepsy do not achieve seizure control and experience related cognitive impairments that severely limit quality of life.

The Epilepsy Foundation and Epilepsy Foundation Eastern Pennsylvania are committed to supporting physician-directed care, and to exploring and advocating for all potential treatment options for epilepsy. We believe bureaucratic processes should not stand in the way of individuals gaining access to clinically proven treatments once they have been reviewed and approved by the FDA and applaud you for your swift action to ensure these individuals do not experience a delay in accessing this treatment option. Please do not hesitate to contact Laura Weidner, Esq., Vice President Government Relations and Advocacy, at 301-918-3766 or lweidner@efa.org with questions or concerns.

Sincerely,

A handwritten signature in black ink that reads "Elizabeth Beil".

Elizabeth Beil
President & CEO
Epilepsy Foundation Eastern Pennsylvania

A handwritten signature in black ink that reads "Philip M. Gattone".

Philip M. Gattone, M.Ed.
President & CEO
Epilepsy Foundation

CC: Mike Brunel, Chief of Staff
Eric Hagarty, Deputy Chief of Staff