



February 14, 2019

The Honorable Gene Suellentrop
Chair, Senate Public Health and Welfare Committee
Kansas State Capitol, Room 118-N
300 SW 10th Street
Topeka, KS 66612

Dear Chair Suellentrop and Members of the Senate Public Health and Welfare Committee:

On behalf of the Epilepsy Foundation and our local affiliate, Epilepsy Foundation of Missouri & Kansas, we urge your support of Senate Bill 93. This bill supports a critical priority for the epilepsy community – access to physician-directed care and treatments. The bill would place limits on step therapy protocols used by insurance companies. Step therapy protocols require individuals to try and fail on a series of medications before they are granted coverage for the medication originally prescribed by their health care provider. The bill would not prohibit these techniques completely, limit the number of steps an insurer can impose, or prioritize the prescribing of brand name drugs over generics. Instead, it would require a clear appeals process and provide certain circumstances when a health care provider and patient can override an insurer's step therapy requirement. Completely limiting access to certain medications is dangerous to individuals living with chronic conditions, especially those living with epilepsy, and it leads to higher overall health care costs.

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 of Missouri & Kansas, advocates and provides services for the almost 30,000 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 characterized by seizures, which are sudden surges of electrical activity in the brain, that affects 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, epilepsy medications are the most common and cost-effective treatment for controlling and/or reducing seizures, and they must have meaningful and timely access to physician-directed care.

Epilepsy medications are not interchangeable, and treatment of epilepsy is highly individualized. There is no "one size fits all" treatment option for epilepsy, and the response to medications can be different for each person. 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.

People living with epilepsy who have their medications switched, or who experience a delay in accessing their medications, are at a high risk for developing breakthrough seizures and related complications including early death. Limits to physician-directed care can also significantly increase medical costs



related to preventable seizures, along with lost wages and productivity, not just for the individuals living with epilepsy but also their families and communities.

For people living with epilepsy, changing medications is not as simple as merely switching the pill they take every day. In order to safely transition from one medication to another, individuals with epilepsy must do so under the close supervision of their prescribing provider and must slowly introduce the new medication to their system until they reach full dosage. During this time, individuals are at a substantial risk of having multiple seizures and related complications, and if the medication fails to work for them, they must slowly wean off the dosage before transitioning to the next medication.

Selection of the appropriate medication to prevent seizures is determined by a number of variables, including type of seizure, seizure frequency, age, gender, and other health conditions. Determining the right medication for a particular person may require trial-and-error, along with close observation of blood levels and side effects.

For these reasons, physicians and their patients need to be assured that the full array of treatment options is available without onerous utilization management protocols like step therapy. The treating physician is in the best position to make the judgment about which medication is most appropriate. The Epilepsy Foundation and Epilepsy Foundation of Missouri & Kansas oppose policies that unnecessarily prolong ineffective treatment and/or prevent individuals from accessing the treatment that their physicians, who provide care based on their expert knowledge and experience, think is best.

The Epilepsy Foundation and Epilepsy Foundation of Missouri & Kansas urge you to support Senate Bill 93 which would provide a clear appeals and exceptions process so that individuals with complex, chronic conditions such as epilepsy have access to the medication they need. Please feel free to contact Laura Weidner, Esq., Vice President, Government Relations & Advocacy at our National Headquarters, at lweidner@efa.org or 301-918-3766 with any questions or follow-up. Locally, you may contact James Townsend, CEO, Epilepsy Foundation of Missouri & Kansas at 816-444-2800.

Sincerely,

A handwritten signature in blue ink that reads "James Townsend".

James Townsend
CEO
Epilepsy Foundation of Missouri & Kansas

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

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