



March 20, 2017

The Honorable Robert B. Jacquard  
House Committee on Corporations  
State of Rhode Island General Assembly  
82 Smith Street  
Providence, RI 02903

Dear Chairman Jacquard and Members of the House Committee on Corporations:

On behalf of the Epilepsy Foundation, our affiliate in Rhode Island, Epilepsy Foundation of New England and the more than 10,000 individuals living with epilepsy in the Ocean State, we urge your support of House Bill 5636.

We urge an early hearing because this bill help to assure people get needed medications in a timely manner, provides continuity of care and increases compliance. People living with epilepsy who experience a delay in accessing their medication are at a high risk for developing breakthrough seizures and related complications including death.

This bill supports a critical priority for the epilepsy community – open access to physician-directed care and treatments. The bill would place limits on step therapy protocols used by insurance companies. Step therapy protocols require patients to try and fail on a series of medications before they are actually allowed to use 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 requirements when medically appropriate. Completely limiting access to certain medications is dangerous to patients, especially individuals 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 more than 3 million Americans with epilepsy and seizures. 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. For the majority of people living with epilepsy, epilepsy medications are the most common and most 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.

As stated earlier, people living with epilepsy who have their medications switched, or who experience a delay in accessing their medication, are at a high risk for developing breakthrough seizures and related complications including 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.

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 the Epilepsy Foundation of New England oppose policies intended to restrict access to physician-directed care. These policies 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 the Epilepsy Foundation of New England urge you to support H. 5636. Please do not hesitate to contact Bill Murphy, Director, Advocacy and Public Policy at Epilepsy Foundation New England at [murphy@epilepsynewengland.org](mailto:murphy@epilepsynewengland.org) or 617-506-6041, ext. 104 with any questions or concerns.

Sincerely,



Susan Linn  
President & CEO  
Epilepsy Foundation of New England



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

CC: Representative Mary Messier – First  
Vice Chairwoman  
Representative Raymond H. Johnston, Jr. –  
Second Vice Chairman

Representative Raymond H. Johnston, Jr. –  
Second Vice Chairman  
Representative Stephen M. Casey  
Representative Michael W. Chippendale  
Representative Antonio Giarrusso  
Representative Raymond A. Hull