June 18, 2018

The Honorable Todd Young
400 Russell Senate Office Building
Washington, DC 20510

Dear Senator Young:

On behalf of the Epilepsy Foundation and our local chapter, Epilepsy Foundation of Indiana, we urge your support of House Resolution 2077, *Restoring the Patient’s Voice Act.* This bill supports a critical priority for the epilepsy community – open access to physician-directed care and treatments. The bill would streamline step therapy protocols for health plans governed by the Employee Retirement Income Security Act of 1972 (ERISA). Step therapy protocols require individuals 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. Completely limiting access to certain medications is dangerous for 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 the at least 3.4 million Americans with epilepsy and seizures. Locally, the Epilepsy Foundation of Indiana serves the almost 70,000 Hoosiers with epilepsy and seizures. Together, 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.

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 Indiana 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 Indiana urge you to support House Resolution 2077. Please feel free to contact Abbey Roudebush, Government Relations Manager at aroudebush@efa.org or 301-918-3784 with any questions or follow-up.

Sincerely,

Ryan Keys
Executive Director
Epilepsy Foundation of Indiana

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