



March 21, 2018

The Honorable Joshua Miller  
82 Smith Street  
Providence, RI 02903

Dear Chairman Miller and Members of the Senate Health and Human Services Committee:

On behalf of the national Epilepsy Foundation, our local affiliate the Epilepsy Foundation New England, and the more than 10,000 individuals living with epilepsy in Rhode Island, we urge you to oppose Senate Bill 2532. This bill would make it harder for people to afford their medications by preventing manufacturer co-pay assistance from counting toward an individual's deductible. This would translate to higher and unanticipated copays at the pharmacy counter because people are not reaching their deductible as early as they used to, undermining affordability, adherence, and health outcomes.

1 in 26 Americans will develop epilepsy at some point in their lifetime. The Epilepsy Foundation is the leading national health organization that speaks on behalf of the 3.4 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. . For the majority of people living with epilepsy, anti-epileptic drugs (AEDs) 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 and prescribed medications. 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. 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. Maintaining seizure control with minimal side effects requires careful evaluation and monitoring by physicians as well as strict adherence to the medication schedule by patients. To change, limit, or deny access to medications could be extremely dangerous.

Senate Bill 2532 would prohibit financial support that manufacturers provide via copay cards and coupons from counting toward an individual's deductible. This would impact each individual differently, but it would often mean high and unanticipated copays at the pharmacy counter when an individual shows up for a refill a few months into the plan year because they are not reaching the deductible as early as they used to. This change in how the deductible is calculated by the health plan would undermine cost-sharing predictability and could impact adherence rates. Individuals may abandon medications at the pharmacy counter or adjust their medication regimen by trying to make their refill last longer and jeopardize their health. People living with complex chronic conditions increasingly face a landscape that makes it difficult to afford the medications prescribed by their provider. This bill would add yet another access



barrier at a time when we need to be focused on ensuring people can afford and get the medications they need to maintain and improve their quality of life.

The issue is particularly important to the epilepsy community because 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 death. Manufacturers' copay assistance for individuals who are struggling to afford their medications, even with insurance coverage, play a critical role in ensuring they can gain and maintain seizure control and avoid increased medical costs related to preventable seizures, along with lost wages and productivity, not just for individuals living with epilepsy, but also their families and communities.

The Epilepsy Foundation and the Epilepsy Foundation New England urge you to oppose SB 2532 and focus on public policies that improve access to and affordability of lifesaving medications for everyone, especially people living with complex chronic conditions like epilepsy. Please do not hesitate to contact Bill Murphy, Director, Advocacy & Public Policy for Epilepsy Foundation New England at [wmurphy@epilepsynewengland.org](mailto:wmurphy@epilepsynewengland.org) or 617-506-6041.

Sincerely,

Sincerely,

A handwritten signature in black ink that reads "Susan Linn".

Susan Linn  
President & CEO  
Epilepsy Foundation New England

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

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

CC:

Senator Gayle L. Golden – Vice Chair  
Senator James C. Sheehan - Secretary  
Senator Jeanine Calkin  
Senator Elizabeth Crowley  
Senator Thomas J. Paolino  
Senator Adam J. Satchell  
Senator V. Susan Sosnowski