EPILEPSY FOUNDATION
New England

Testimony to the
Joint Standing Committee on Health Coverage, Insurance, and Financial Services
Thursday, March 27, 2025

IN SUPPORT OF LD 1053
"An Act to Ensure That Rebates from Prescription Drug Manufacturers Are Passed on to Patients at Pharmacies"

Offered by
Kristen McCone Gordon
Associate Director, Advocacy & Public Policy
Epilepsy Foundation New England

TO:
Chair Donna Bailey
Senator Joseph Baldacci
Senator David Haggan
Chair Lori Gramlich
Representative Poppy Arford
Representative Michelle Boyer
Representative Marygrace Cimino
Representative Sally Cluchey
Representative Paul Flynn
Representative Robert Foley
Representative Anne-Marie Mastraccio
Representative Joshua Morris
Representative Rolf Olsen

Dear Chair Bailey, Chair Gramlich, and distinguished members of the Joint Committee on Health Coverage, Insurance, and Financial Services:

On behalf of the Epilepsy Foundation New England, and the more than 14,100 individuals living with epilepsy in Maine, we urge you to support LD 1053 regarding pharmaceutical rebates.

Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions and is unfortunately far more common than most people realize. 1 in 10 Americans will experience a seizure and 1 in 26 Americans will develop epilepsy at some point in their lifetime.

For most people living with epilepsy, anti-epileptic drugs (AEDs) are the most common and cost- effective treatment for controlling and/or reducing seizures. However, there is no "one size fits all" treatment option for epilepsy, and the response to medications can be different for each person.

Additionally, many people with epilepsy, especially those living with rare epilepsy syndromes, are on several medications for their seizures and accompanying co-morbidities. As one can imagine, needing several high-cost medications often has an unsustainable cumulative financial effect for those living with this disease.

LD 1053 would provide needed relief and have a significant impact on the daily lives of the people we serve, as well as countless others in Maine with chronic conditions who struggle to afford life-saving prescriptions.

Under the current insurance system, rebates on pharmaceutical drugs are negotiated by PBMs in exchange for formulary placement. This is problematic for many reasons, chief among them is instead of passing these savings through to patients who are struggling to afford lifesaving medications, the rebates are instead retained by the PBMs and health insurers. As you will hear from our colleagues in the Patient Pocket Protector Coalition, this means that our most vulnerable citizens do not benefit from the lower net price of their medications and are paying more than they must.

The bottom line is that patients who pay a premium for insurance coverage should benefit from the discounted price not the PBMs. Rebates should instead be shared at the pharmacy counter.

This isn't just the right thing to do for individuals, it's what's best for the entire system. When patients cannot afford their medications, they may ration or abandon their prescribed therapy, leading to painful and costly complications. We hear of this happening all the time and it's not unique to the epilepsy community. Rationing medication not only can lead to tragic outcomes, but it affects the entire system by driving up overall health care costs.

Now is the time to rein in costs and increase transparency by regulating PBM practices and sharing rebates with patients. Providing at least some financial relief as offered in LD 1053 offers some hope and support for families and individuals who are really struggling and need it the most.

We respectfully urge you to support this legislation.

I am happy to answer any questions and can be reached at kgordon@epilepsynewengland.org

Sincerely,

Kristen McCone Gordon
Associate Director, Advocacy & Public Policy
Epilepsy Foundation New England