

Hearing Date-3/27/2025

To the Health Coverage Financial Services Committee,

I want to begin by asking you two questions:

1. Have you ever found yourself holding a mirror under your child's nose just to confirm they're still breathing, or gently resting your hand on their chest while they sleep, making sure you can feel that steady rise and fall?
2. Have you ever walked into your child's bedroom in the morning, holding your breath, because they've been asleep longer than usual, and the fear of discovering something unimaginable is all too real?

These questions are not hypothetical—they are my reality. Today, I am here to testify in support of LD 1053, “An Act to Ensure That Rebates from Prescription Drug Manufacturers Are Passed on to Patients at Pharmacies.”

My name is Kristine Binette. I live in Cumberland County, and I am the mother of a 17-year-old daughter with epilepsy. I also serve as the Community Education Manager for the Epilepsy Foundation New England.

Each year, more than 1 in 1,000 people with epilepsy die from a seizure. This is called SUDEP—Sudden Unexpected Death in Epilepsy. When seizures are not well controlled, that number increases drastically to 1 in 150. Achieving seizure control is the best way to prevent SUDEP. Thanks to advances in medicine, newer seizure medications target specific receptors in the brain and the sodium channels of neurons, providing patients with better seizure control. These medications should be accessible to anyone with epilepsy.

My daughter is currently taking an expensive brand-name seizure medication—one of the first that has helped control her seizures. Without this medication, she falls into that high-risk category. My husband's health insurance has a high deductible, and each year, we fight to meet it. Pharmaceutical companies offer rebate cards to help families like ours afford essential medications. However, when the rebate runs out, we don't suddenly find relief in having met our deductible. Instead, we are forced to start over from the beginning, and we find ourselves having to choose between the cost of food and our daughter's health.

No family should have to choose between a less expensive, less effective medication with more side effects over a newer, more targeted treatment that offers real seizure control. Yet, this is a reality that I not only face as a parent but also witness in the families we serve. I have seen parents beg for help when their child finally achieves seizure freedom—only to lose access to the very medication that made it possible because their rebate has expired, and their deductible remains unmet.

It is unacceptable that pharmacy benefit managers profit from my daughter's health while I bear the financial burden once the rebate runs out. This double-dipping must stop. The savings should be passed on to families like ours, reducing our out-of-pocket expenses.

Passing this act would ensure that the financial relief intended for patients actually reaches us. It would transform each pharmacy visit from a moment of financial anxiety to one of assurance—that we can keep our children healthy and safe, that we won't have to wake up one morning to the worst nightmare any parent can imagine.

This is about fairness, transparency, and, most importantly, creating a system that prioritizes people over profits. The current system is failing us, but we have the opportunity to fix it. Let's commit to ensuring that rebates serve their true purpose—supporting patients, not enriching corporate interests. The health and well-being of our children depend on it. My daughter depends on it. Please do not let her become the 1 out of the 150.

Thank you.

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