

My name is Rose Keller, I'm 22 years old, and I'm a resident of Brunswick. I also have cystic fibrosis, a rare genetic condition that affects my lungs. When I was born, the life expectancy of someone with CF was in the 30s. Today, thanks to the advancement of modern medicine, that number is closer to the mid-fifties.

No small part of that massive leap is thanks to Vertex Pharmaceuticals, the drug company that manufactures Trikafta, a drug that I have taken. It is a first of its kind medication that treats the underlying cause of cystic fibrosis for over 90% of patients. The day that the FDA approved Trikafta prompted delirious joy from the cystic fibrosis community. For me, that delirium quickly subsided when I found out what the drug would cost: upwards of three-hundred-thousand dollars per year. Despite the enormous value Trikafta brings to patients, that lavish sum is much too great a burden to impose on our healthcare system. Patients need access to drugs that work at prices they can afford.

My parents' insurance, which I am still a beneficiary of, is willing to cover the cost of my Trikafta – for now. The copay I owe for the drug, in addition to the costs associated with the other prescription medications I take, comes out to well over twenty-five hundred dollars every year. My out-of-pocket costs have steadily grown in recent years, at a rate that imperils my financial independence.

When drug companies are allowed to demand whatever price they name, insurance companies must compensate for that by raising premiums. We have seen this happen in Maine just last month, when Bureau of Insurance Superintendent Bob Carey announced approval of the 2025 health insurance rates for Maine's individual and small group market. Though the Bureau successfully worked to lower initially proposed rates by insurers and reduce geographic disparity among northern and southern Maine, across the board, rates went up. The press release cited "the accelerating cost of prescription drugs" as one of the contributing factors to the increase in the cost of health insurance. I refuse to sit idle while Vertex and other pharmaceutical companies force higher premiums on my friends, neighbors, and community in Maine to satiate their endless greed. That pill is too tough to swallow.

Other states have started to address by creating Prescription Drug Affordability Boards with actual regulatory authority to set upper payment limits. The pharmaceutical industry has,

in turn, opposed the creation and proceedings of these agencies in state government to limited success. Though Colorado's PDAB faces a lawsuit brought by Amgen, the federal judiciary has consistently rejected similar legal arguments in the litigation challenging Medicare price negotiations.<sup>1</sup> A state program could imitate the federal program and withstand legal challenges.

I look forward to the day when the state of Maine has a Prescription Drug Affordability Board with the statutory authority to set upper payment limits, or something similar. Until then, if the current trend continues, the healthcare system will become too expensive to function. My future plans – to go to law school, to have a family, to build a life here in Maine – are in jeopardy until something changes. Thank you for the opportunity to submit public comment.

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<sup>1</sup> <https://oneill.law.georgetown.edu/administration-announces-medicare-negotiated-prices-as-courts-continue-to-reject-challenges-to-the-program/>