Testimony in support of LD 697: An Act to Direct the Maine Prescription Drug Affordability Board to Assess Strategies to Reduce Prescription Drug Costs and to Take Steps to Implement Reference-based Pricing

Good afternoon, Senator Bailey, Acting Chair Gramlich and members of the Committee on Health Coverage, Insurance, and Financial Services,

Thank you for this opportunity to testify in support of LD 697. My name is Rose Keller, I'm 23 years old, a recent college graduate, and I live right here in Augusta. 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 their 30s. Today, thanks to the advancement of modern medicine, that number is somewhere in the low 60s.

No small part of that massive leap is thanks to Vertex Pharmaceuticals, the drug company that manufactures Trikafta, a drug that I take. It is a miraculously effective medication for 90% of the CF community, but it has one huge drawback: Vertex Pharmaceuticals has leveraged its monopoly to set an unconscionably high price for Trikafta. At over three hundred thousand dollars per year, this medication's price tag far outpaces its substantial benefits. That lavish sum is much too great a burden to impose on our healthcare system.

When drug companies like Vertex 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 a few months ago, the Bureau of Insurance Superintendent Carey announced the

approval of the 2025 rates for Maine's individual and small group market, and though the Bureau successfully worked to lower initially proposed rates by insurers, across the board, rates went up. I refuse to sit idle while the pharmaceutical industry forces higher premiums on my fellow patients, neighbors, and community in Maine to satiate their endless greed.

We need access to drugs that work at prices we can afford. Allowing pharmaceutical companies to price-gouge beyond any semblance of affordability causes harm to patients – CF and otherwise. My parents' insurance, which I am still a beneficiary of, is willing to cover the cost of Trikafta – for now. But my copays and out-of-pocket costs have steadily grown in recent years, at a rate that imperils my financial independence. Ultimately, I and patients like me will be forced to delay or entirely go without treatment if these pricing trends continue.

Other states have responded to the rising costs of prescription drugs by creating empowered Prescription Drug Affordability Boards with the necessary tools to address it, chief among them being the statutory regulatory authority to set upper payment limits. In directing our PDAB to assess strategies like implementing upper payment limits, this bill is a welcome first step on the path to protecting sustainable access to life-saving treatments for patients like me. As a state agency charged with reducing the impact of prescription drug costs on the State's health care system, Maine's PDAB will be better positioned to take action against drugs with generous assistance programs that are otherwise contributing to systemic affordability issues, like Trikafta.

The pharmaceutical industry and the astroturf groups it funds will try, if they haven't already, to convince you that PDABs pose a threat to patients – I am here to say precisely the

opposite is true. I look forward to the day when the state of Maine has a Prescription Drug Affordability Board with the statutory authority to not just consider UPLs, but implement them, too. 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 unless we can find a solution. LD697 is part of that solution. Thank you for the opportunity to provide this testimony.