Susan Kinney Kennebec County LD 1636

This testimony is in support of LD 1636 An Act To Reduce Prescription Drug Costs by Using International Pricing.

Committee on Health Coverage and Financial Services

Senator Sanborn, Representative Tepler and Members of the Committee,

Hello, I am Susan Kinney of Kennebec County, and I am here to testify on behalf of my family, including my daughter, Marissa, who is now 24 years old, in support of LD 1636 An Act To Reduce Prescription Drug Costs by Using International Pricing, which would address rising prescription drug and health care costs in Maine.

I would like to explain the impact of the continued rising health care costs, in particular prescription drugs, on my family and our business. Our struggles with health care are very frustrating, but I will be concise.

In 2015, my 17-year-old daughter, Marissa, was diagnosed with Crohn's Disease. It is an inflammatory bowel disease that causes chronic inflammation in the gastrointestinal tract. I cannot even begin to express what an oversimplification this statement is. The disease is unpredictable and can spiral out of control, quickly leading to hospitalization.

Over the years, we have struggled to access affordable coverage that would meet our health care needs and provide Marissa with the medication she needs to not only be healthy, but to thrive. The number of health insurance providers who will cover Remicade is extremely small. Keeping her healthy has not been easy and we constantly worry what her future holds if she cannot access the medicine and care necessary. Currently, our family coverage costs us over \$1,800 a month. The out-of-pocket max for in-network services is \$7,050 individual and \$14,100 family. The out-of-network OOP max is \$21,150 individual, \$42,300 family. This year, we were again forced to choose a different plan because our current one was no longer offered, raising our deductibles yet again.

Marissa currently takes Remicade, a prescription infusion treatment that costs about \$5,900 every eight weeks - this is on top of her other health care needs. Included in this cost is the medicine, which costs \$4,300, and the infusion center fee of \$1,600. She is currently on the lowest dosage. If the dose increases, so does the cost. Fortunately, the infusion clinic offers a prescription drug patient assistance program called Janssen CarePath that is offered by Johnson & Johnson. While this program does cover the cost of the medication with a yearly limitation, it does not cover the facility costs until the deductible is met. Last year, I received a bill for two years' worth of infusion center costs. They would only allow me a year to pay it off. I share this because normally I am given 36 months to pay off medical expenses. In addition to this, I currently have seven different accounts that I am paying on for our family medical expenses - one of which will take 7 years to complete. Please note, this account is for Remicade and its administration expenses before we qualified for the Janssen Care Path program. Marissa's medical expenses are continual and begin again every January. As her parents, we worry how she will in the future maintain her health and lead a productive life with the continued rising costs of Remicade and its administration. Remicade was approved for Crohn's in 1998. There is no reason for the continual increase in price.

Again, there is so much more I could say about all this, but my time is limited. We can proudly say that our daughter graduated from the University of Maine, but she will need an amazing job with generous medical benefits to continue with her disease treatments. With the ever-rising cost of prescription drugs, insurance premiums and deductibles, she will never be a self-employed business owner. We are fortunate that the medicine is working and realize we are not alone in our struggles. Therefore, I am asking that you please support LD 1636 and do what you can to address high

prescription drug and health care costs in Maine. The growth of small business and retention of college graduates is important to the state and for this to happen, the state must provide affordable medical coverage and prescription costs for individuals like Marissa to maintain a healthy, successful life.

Sincerely, Susan Kinney Kennebec County