

****Note: this testimony replaces previous testimony by Susan Kinney that was submitted in error last week.****

This testimony is in support of:

LD 120, An Act To Lower Health Care Costs through the Establishment of the Office of Affordable Health Care

LD 1117, An Act To Prevent Excessive Prices for Prescription Drugs

LD 675, An Act to Protect Maine Consumers from Unsupported Price Increases on Prescription Medicines by Creating an Independent Review Process

LD 686, An Act To Increase Prescription Drug Pricing Transparency

LD 673, An Act To Create the Insulin Safety Net Program

Hello, I am Susan Kinney of Kennebec county and the wife of a small business owner.

I am here to testify on behalf of my family, including my daughter, Marissa, who is now 23 years old, in support of this Rx bill package / the Office of Affordable Health Care to address rising prescription drug / health care costs in Maine.

I would like to explain the impact of the continued rising health care costs 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. 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 \$1,900 a month. The in-network deductibles are \$5,500, individual, and \$11,100 family. The out-of-pocket max is the same. The out-of-network OOP max are \$16,650 individual, \$33,300 family.

Marissa currently takes Remicade, a prescription infusion treatment that costs about \$5,922 every eight weeks - this is on top of her other health care needs. We have to pay out of pocket for these treatments until our deductible is met each year. After the deductible is met, the treatments are covered by our insurance 100 percent. Included in this cost is the medicine, \$4,300 and infusion center fee of \$1,600. She receives infusions every 8 weeks and is currently on the lowest dose. If the dosing increases, so does the cost by thousands of dollars. At one point, we were told by our insurance company that our coverage was ending in our location and for approval of coverage, a Pennsylvania site was recommended. I researched and found a clinic in Maine that was in-network

and provided coverage. I had less than 8 weeks to find a clinic, have the paperwork sent over and the infusion approved by the insurance company. It was at this facility we enrolled into the Janssen CarePath. This is a prescription drug patient assistance program with drug maker Johnson & Johnson that may be able to help with the cost of my daughter's medication. I am unsure as to the amount, and just received a bill for the infusion center from last year. I am waiting to find out the final cost for last year. In addition to this, I currently have 8 different accounts that I am paying on for our family medical expenses - one of which will take 7 years to complete. They 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 is graduating from the University of Maine, but she will need an amazing job with generous medical benefits to continue with her disease treatments. With the cost of prescription drugs and the cost of medical insurance, she will never be a self-employed business owner because of the rising cost of insurance premiums and deductibles. 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 these prescription drug bills 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