

**Testimony of Sarah Lukianov**  
**LD 673, An Act to Create an Insulin Safety Net**  
**April 13, 2021**

Dear Members of the Committee,

My name is Sarah Lukianov from Bath, Maine, and I've had type 1 diabetes for 24 years, diagnosed when I was in the fifth grade.

I'm here to support LD 673, modeled after the Alec Smith Insulin Affordability Act, named for Alec Smith, a type 1 diabetic who lost his life when a lack of affordable insulin access led his body to suffer diabetic ketoacidosis.

I'd like to tell you what it feels like to have diabetic ketoacidosis, or DKA, from someone who knows: me.

It feels like you're burning from the inside. Exhaustion pulls at every limb until you can barely lift a finger. Breaths come in gasps between the stabbing pains in your stomach. It is both excruciating pain and absolute terror. You feel like you're dying, and that's because you are.

I'd also like to tell you what it's like to ration your insulin, as I have done.

Health insurance companies often approve just enough insulin for a person to get by on for a single month if everything goes according to plan. But we are not robots, and try as we might, it's difficult to recreate the function of the human pancreas. Some months we require more insulin than others; some months we require less. But rarely is there surplus. Rarely is there enough to stockpile even one extra vial for our own "safety net," tucked in the corner of our fridge, where our insulin is meant to be stored.

I depend on two insulins: a long-acting and a short-acting. A few years ago, I dropped the vial of my long-acting insulin on the kitchen floor, where it shattered. I begged my insurance company to cover an emergency vial, but they just told me I could pay over \$300 out of pocket to buy the insulin at a pharmacy. I was shocked at the price, so I decided I'd wait the days until I could pick up the next month's supply. I figured I could make it with just my fast-acting insulin if I rationed what I had left of it. This led to me going three days without enough insulin, sending my body into the beginning stages of DKA, the same thing that almost killed me when I was first diagnosed when I was 10, the same thing that killed Alec Smith.

Within two days of breaking the vial, I remember walking up the stairs of my house after work, gasping for breath, wondering if I was about to die.

I'm lucky that DKA didn't kill me like it has so many others. But it has killed far too many others who have had to ration insulin because of the cost, even though synthetic insulin has been around for 100 years.

In fact, synthetic insulin celebrates its hundredth birthday this very year. The patent was sold for \$1 by insulin's co-discoverer, Dr. Frederick Banting, who upon sale of the patent reportedly said, "Insulin belongs to the world, not to me."

Pharmaceutical companies don't seem to agree with Dr. Banting, charging over \$350 for something that costs them less than \$10 to produce.

There is no alternative for type 1 diabetics; without insulin, we die quickly and painfully.

I am asking you to help protect the insulin-dependent Mainers whose lives are repeatedly endangered by the well documented price gouging at the hands of big pharma. Please support this bill so that we can keep insulin-dependent Mainers secure in the knowledge that they never have to fear the possibility of running out of insulin.

Thank you.