

TESTIMONY OF HILARY D KOCH

In Support of LD 1729,

Resolve, To Assess the Feasibility of the Production of Insulin in Maine

Health and Human Services Committee

February 1, 2022

Senator Claxton, Representative Meyer, and distinguished members of the Health and Human Services Committee, my name is Hilary Koch, and I live in Waterville.

I have had a lot of jobs in my lifetime. I've been a teacher. I've been a college instructor. I've been a Policy Manager for the US division of an international company where I worked on federal insulin bills. But the most important job I've ever had is being my son's pancreas. My youngest son was diagnosed with type 1 diabetes when he was 2 ½ years old. Type 1 diabetes is an autoimmune disease. My son is insulin dependent and without artificial insulin, within hours his blood will start to turn acidic, and he will die a painful death within days. So, my primary job for 13 ½ years has been to be his pancreas.

When my son was diagnosed, I learned quickly that that insulin was life sustaining, but that it also could kill him. It's a balancing act. If I give too much, he could die. If I give too little, he could die. Our job as parents is to keep our children healthy and safe. Now imagine learning that one mistake as a parent could kill your child. Yet, it's not enough to worry about managing diabetes, we also must worry about how to afford insulin.

On average it costs \$5 to make one vial of insulin, but without insurance a 3-month supply of my son's insulin is \$3,399.99. This excludes the supplies needed to get the insulin into his body. And it's easy to believe Big Pharma when they tell you PBMs drive up the prices, or that they offer Patient Assistance Programs to provide those in need with access to insulin, but I promise you this is simply not true. Eli Lilly, Novo Nordisk, and Sanofi, set the list price. They've abused the patent system to prevent competition with cartel-like practices and they've raised prices by over 1,200%.

We know that 1 in 4 Americans ration their insulin because they can't afford it. Last year with LD 673, we heard doctors and patients testify about times when people couldn't afford their insulin. We heard from three people who lost loved ones due to insulin rationing, including Catherine Begin, who lives down the street from me, whose son Nick died due to insulin rationing. I have even had to ration insulin for my son when our insurance company tried to switch him to a different brand. My son also testified last year. He told the committee how he just wanted to be a normal teenager who thinks about basketball, yet he worries about what will happen when he grows up. My 15-year-old is afraid to grow up, not because he doesn't want to be an adult, but because he doesn't want to die because he is afraid he won't be able to afford his insulin.

I've helped to pass several insulin bills here in Maine, including two emergency insulin bills and a co-pay cap. I want to be clear that these were important steps but none of these has done anything to lower the price of insulin. Pharmaceutical companies especially like co-pay caps because they don't impact their bottom line. But while on the surface patients seem to pay less, in our case paying \$35 at the counter, the cost is often shifted through insurance premiums. Also, it's important to recognize that the most vulnerable, those without insurance and those with high-deductible plans, do not benefit from co-pay caps. So, LD 1729 is essential in tackling the insulin pricing crisis.

My son also has something called hydrocephalus, an incurable disease that has led to five neurosurgeries in his lifetime, four of which were emergency surgeries. So, when I say the following to you, I want you to really understand the seriousness and gravity of my words: There is nothing more important to me than making insulin affordable. LD 1729 is similar to legislation adopted in other states and is essential for Maine to take important steps to make insulin affordable for Mainers. I encourage you to support LD 1729.