

TESTIMONY OF HILARY D KOCH

In Support of LD 329, An Act to Ensure Health Care for All Maine Residents Joint Standing Committee on Health Coverage, Insurance, and Financial Services May 9, 2023

Senator Bailey, Representative Perry, and distinguished members of the Joint Standing Committee on Health Coverage, Insurance, and Financial Services, my name is Hilary Koch and I live in Waterville.

For many years, my husband and I struggled with infertility, and we felt blessed to have two children that were almost a decade in the making. When we took our youngest for his six-month checkup, we were asked if we had any questions or concerns. We said we were worried about the size of his head – it was unusually large. He was wearing hats that fit our two-year-old. His pediatrician was worried too, and he scheduled a CAT scan for the following Monday.

But we didn't make it to Monday. My son had a seizure that night and was rushed to the ER. He was diagnosed with hydrocephalus. A condition in which the ventricles inside the brain fill with fluid causing pressure on the brain, the eyes, and the skull. And much like a water balloon continuing to expand, failure to relieve the pressure would prove fatal. Surgery was essential. There was no cure. In fact, because there wasn't a cure and technology was imperfect, we were told he could face more than 30 surgeries in his lifetime. A shunt was placed, and his surgery carried a price tag of over \$80,000.

In addition to just being a parent, I needed to learn everything I could about hydrocephalus, how to advocate for my son, and everything about health insurance benefits. I had to ensure that we always had insurance because we knew more surgeries could come at any time.

Two years later, he was diagnosed with type 1 diabetes. Another incurable condition. Even more relentless.

We've spent thousands of dollars. And I've spent countless hours so he could have access to the proper care and supplies he has needed just to stay alive.

My son turns 17 in a few weeks. He has had five neurosurgeries and he manages his type 1 diabetes like a rockstar. His doctors are in awe of him. He is thriving. But he will always require access to health insurance to stay alive.

I've been a caregiver and I've also worked in health policy. I've helped shape state and federal bills and worked with lawmakers and patient advocates on both sides of the aisle to help ensure access to affordable prescription drugs.

Through all of this, it is clear that healthcare should be a basic human right, not a privilege. But how we achieve that is complicated. And I have worked with many extraordinary professionals along the way. Yet nothing can replace patient voices. They simply must be at the table in this discussion.

However, looking at the proposed working group of LD 329, patient voices are absent. So, I implore you to include two members that would represent the patient community. Perhaps a senior citizen and someone living with a medical disability. These people rely on our healthcare system and would bring essential perspectives unique to other members proposed in the current amendment. Then I urge you to support LD 329.