

**TESTIMONY OF HILARY D KOCH
Maine #insulin4all Chapter Leader for T1International**

**In Support of LD 673,
An Act To Create the Insulin Safety Net**

Joint Standing Committee on Health Coverage, Insurance, and Financial Services

April 13, 2021

Senator Sanborn, Representative Tepler, and distinguished members of the Committee, my name is Hilary Koch, I live in Waterville, and I am the Maine #insulin4all Chapter Leader for T1International, a global nonprofit organization fighting for access to affordable insulin and diabetes supplies.

I have 3 minutes to save my son's life

It took 7 years to have my first son.
9 to have my second.
Ten fingers and toes,
They were all there
6 months later,
I became Mama Bear.
My son had hydrocephalus,
His brain fatally swelling.
I didn't understand,
Though the doctor's faces were telling.
His first neurosurgery wouldn't be his last.
I had to learn about insurance,
And I had to learn fast.
"He may never speak, or walk,
We'll only know with time."
One thing was certain,
Good insurance would be prime.
"We can do this,"
I told my husband,
"I'll give up my career,
We'll be fine."

And life became better.
At least, for a time.

Two years later, our world stopped.
And hydrocephalus became a cake walk.

"It's type 1 diabetes," they told us,
"It's not like type 2."
He can't take a pill, and exercise won't do."
I held him down, while he screamed,
Pricked his fingers, gave him shots.
I didn't have a medical degree,
But this was our lot.

"Things will get better.
It's manageable, right?"
Let me tell you the reality of diabetes in America,
It's always a fight.

My son may live 10 years fewer,
Because he has type 1.
He may lose his eyesight,
His limbs,
His thumbs.

This disease has already taken so much. He's missed thousands of hours of sleep, recess and parties. He waits to eat breakfast, lunch and dinner. He's a human pincushion. A cyborg. And no, it doesn't get easier. It's *a/ways* hard. It's always scary. One mistake and he's dead.

Insulin is cheap to make.
Pharma *knows* my son needs it.
Raising prices like a cartel,
Their greed *grows* as their stocks split.

1 in 4 ration insulin.
We've done it too.
Pharma knows, doesn't care.
Though they'll claim that they do.
"Hey, we have coupons!
Here, we'll give you five!"
Are you kidding me?
No one in America, should need a coupon,
To stay alive.

So, I won't tell my son, to follow his dreams,
And find his true self.
"This is America, Son,
Put those dreams on a shelf."
He must always have a job,
And one with good insurance,
Without it, his fate is sealed
I give you my assurance.
His name could join others, like
Alec, Jesimeya, Allen, Nick, and Shane.

Will those in power,
Step up?
Or am I speaking in vain?

Pharma's going to talk about innovation,
And states' limits.
"Your bill is illegal,
They're going to fume."
I'm begging you today,
Wield your power,
Lower the boom.

You see, my son never signed up.
As a donor for pharma.
He's only 14.
It's not his duty to fund innovation,
For future medications,
For you or for me.

\$5 to make one vial.
\$339.99 to purchase.
Over \$1,000 for one month.
11 years until my son ages out of our insurance.
3 minutes to save his life.
LD 673 could save his and others.