Re: HB 2601 February 10, 2020

SPEAKER

This is my 6-year-old, Maggie, and this is our story.

Maggie was born in November of 2013. We had a perfectly normal pregnancy, an uneventful, un-medicated vaginal birth. She scored high on the APGAR. She was the last of our 3 babies, the person that completed our family.

Just like our older two, we decided to follow the routine vaccination schedule starting with the vitamin k shot that is given to newborns. I had no idea what it was for. I just knew that it was there for a reason so why not. 45 minutes after my baby received the routine vitamin k shot I noticed she was turning gray.

Maggie had gone into respiratory distress, from an "unknown illness".

I watched as they took my newborn into the nursery, and hook her up to oxygen. I watched as her doctor, my OB, run test after test, trying to figure out what could have caused my kid to decline so rapidly. He sat on my hospital bed, head in hands, a look of defeat on his face and told me she had "pneumonia like symptoms, and we don't know why. We are thinking it was likely caused by bacteria in the air combining with something from the birth canal, we could be wrong".

We were not allowed to hold our newborn because her oxygen levels would decline. After 2 days at our hospital, the doctor decided that it would be best for Maggie to be lifeflighted out to Wichita so the NICU there could find out what was going on.

The doctor there said the same thing our doc at home said. They weren't sure what caused it, they didn't know exactly how this could have happened, they could only just guess. No answers. None. After 2 weeks in the NICU, we finally got to go home. It was wonderful! We thought this was the extent of it.

As Maggie got older, we noticed she was behind when it came to rolling, crawling, walking, talking. Even more so after we'd take her to get her shots. She would sleep for days. She would be fussier. She was not ok.

We never put two and two together. I wish we had.

My baby was diagnosed at 2 with developmental delays and sensory processing disorder. Certain noises, like the sound of Walmart shopping carts on their tile floors, would cause a meltdown. Textures of certain foods and of different clothing items caused meltdowns and unimaginable screaming fits. Large crowds or family functions would cause Maggie to run away. She couldn't talk to us to tell us what was wrong. She was unable to potty-train until May of 2019 at 5 years old. She couldn't handle being around her peers.

At 4, she was diagnosed with Autism Spectrum Disorder along with developmental delays, speech apraxia, and sensory processing disorder. Which means she couldn't handle seeing Santa or the Chick Fil A cow. It would cause a meltdown. Family get-togethers, birthday parties, having friends over for dinner- all too much for Maggie to handle. We had to get cameras for our property to make sure she didn't unlock the front door and run into the street or climb the fence. A GPS tracking device to make sure that when we weren't with her, we knew where she was just in case she decided to walk off. She didn't develop communication skills good enough for others to understand until this year and after each

round of shots, she would regress both in behaviors and in speech. It felt like 2 steps forward, 3 steps back. A constant tug of war over my child's development and not having a reason as to why this was. At 5, she received an MRI and they found scar tissue on the left side of her brain from swelling that occurred.

I questioned the vaccines in my head. I wondered if they had any hand in this. I never voiced it though. I just quietly started to research. I asked for her medical records from birth to current. It was like clockwork. Shots-regression. Shots-regression. I felt so betrayed and guilty for not realizing this sooner. The lack of real information, proper testing, to be out there, for a warning from the manufacturers. For anything. We thought we were keeping her safe, not causing her brain damage.

When you have a child with special needs, you learn to be patient, and to fight productively. We have to fight for her to get the services she needs. We have to wait on countless waitlists for waivers, behavior therapy, speech therapy, occupational therapy. We have to patiently save up money to make sure sensory needs are met in our home to coincide with the various therapies recommendations to help her to learn things like self-regulation instead of self-harm. We have to keep up on KSDEs Special Education procedures and laws to make sure she's receiving what she needs through her school. We had to learn the IEP process and FAPE and IDEA. It's a totally different world that is struggling to keep up with the demands that are needed to accommodate kids damaged by these safe and affective routine vaccinations that are not held to the same standard as Gerber Baby Food.

If we do not have a choice in whether or not we vaccinate, and are forced to maintain an unrealistic vaccine schedule, no exemptions, my Maggie will regress severely, and all the progress she's worked so hard to achieve will be lost. All that we've had to fight for, wait on, learn about, will have been for nothing.

I am so incredibly thankful we saw the correlation between her regressions and when she had shots. I am so incredibly thankful it's not worse. And I am so incredibly heartbroken for my baby, who will go through life not knowing that the hurt, struggle, and frustration of doing daily tasks is all caused by something that could have been so easily prevented.

Please do not make vaccinations mandatory. Please consider and think about Maggie and stories like hers before making a decision that would be damning to so many. Show your people that you see them, more than you see dollar signs.

Thank you for your time,

Kelly and Maggie Stewart Wichita, KS