



Proponent, Simon's Law-HB 2307

March 21, 2017

House Federal & State Affairs Committee

Chairman Barker, and members of the committee

I support Simon's Law.

I am a Kansas mother of 8 children, ranging in age from 33 to 7. Seven of them are my biological children, and our eighth was placed into our lives through an amazing series of events.

Both our youngest biological child and our adopted child have extensive special needs. Our daughter **Tatum** was prenatally diagnosed with Trisomy 18, like Simon, the namesake of the bill before you. Also diagnosed was a large posterior encephalocele (a fluid filled sac the size of her head, growing at the base of her skull), a Ventricular Septal Defect of the heart, and several other "markers" which led our perinatologist to give Tatum a **fatal diagnosis**, prior to her birth.

We were blessed to have met with the lovely ladies at Alexandra's House (a perinatal hospice home in Kansas City, MO) and they walked us through making a birth plan that allowed us to stand up for Tatum's precious moments following birth. We met with a team of doctors, nurses, and hospital personnel prior to her birth and made our desires known and documented. **Tatum has far surpassed any of the prenatal and postnatal prognoses that were given to us**, and on February 10 of this year she will celebrate her 9th birthday.

Many of the prenatal diagnoses were spot on. Some were overstated, and some were not possible to diagnose until further testing following her birth. She has a plethora of issues, and though she is healthy and a daily blessing, she does face a life that is different from that of our typical children.

Our adopted child, **Zachariah**, came into this world without a birth plan. He was born to a young, unmarried couple, who had issues of their own. They were not prepared for a baby born without a significant portion of his skull, a large occipital encephalocele that contained a portion of his brain (which had to be removed), or the accompanying difficulties of caring for a medically fragile infant.

A few days after his birth, he suffered a long period of apnea and **because he had a DNR, he was removed from monitors, wrapped in a blanket, and handed to his biological mother**. Several minutes into the episode he **self-resuscitated**, and at that point his young parents **asked medical personnel to do all they could for him**.

Zachariah came into our lives when he was a month old, and we were warned that his life would be very short. In fact, we were told he would likely not live out the month and that the best case scenario was a 3 to 5 year life span, fraught with life threatening seizures and bouts of pneumonia. **We were also warned he would exist in a semi-vegetative state.**

Zachariah is 7 1/2 now, he has never suffered a single seizure, nor has he ever experienced a bout of pneumonia. The portion of his brain that was removed was thought to contain his visual cortex and we were told he would be blind, but he sees! He has cerebral palsy, autism, profound global delays, and hemiplegia on the right side of his body. But **he is a delight.** He does not know a bad day, only a bad moment, and then he puts that award winning smile back on his face and marches on!

When we adopted him, **we removed the DNR** that had been placed in his medical records. I honestly do not know that I could make the choice to remove one of my children from life support. I laid one of my adult children to rest in 2010, and can tell you the loss of a child is devastating.

I think every parent of a medically-fragile child should be aware of the choice to sign a DNR for their child, and I would hope that choice could be offered tactfully. But I stand firmly against medical professionals making a life choice for an infant or child based on a prenatal diagnosis, or set of tests.

Tatum has had full genetic testing and her **particular chromosomal tripling has never before been documented** or journaled. Her life was judged by an unknown...and they were wrong!

I was blessed to have Alexandra's House to stand by my side and help me stand tall for my unborn child. It prepared me for several more times I would have to fight for her life and her rights. And it prepared me to open my heart and life to Zachariah. He needed a fighter on his side.

Please pass **HB 2307**, Simon's Law.

Thank you for your time.

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