

Proponent, Simon's Law- HB 2307

House Federal & State Affairs cmte – Mar. 21, 2017

Hello, my name is Scott Crosier. I am Simon's Father. I reside in St. Louis, Missouri, with my beautiful family, but I grew up in Seneca, Kansas and graduated from K-State. My family and I visit Kansas 3-4 times a year and consider it home for all of us.



I'm asking you to put yourself in our shoes as a parent, grandparent or guardian watching your child that you have prayed for, longed for, and waited for-- being treated as a label, an object, not a person. Simon is the price we paid for the violation and removal of our parental rights, if not his human rights.

Anyone who knows me will tell you that I am not afraid to speak my mind and I had my own forceful Simon statement that I repeated often to my son's doctors when I became impatient with their negativity. "WE WILL NOT DO ANYTHING TO EXPEDITE HIS DEMISE."

Everyday life in rural Kansas meant taking care of your neighbor. My strong moral upbringing blends with my tax accountant training to leave little room in my steadfast personality for imprecise communication. So I was especially frustrated by the inability of Simon's physicians to share any concrete opinions about our son's best treatment options or any life sustaining measures that would be taken. Frankly, they never wanted to tell us squat.

I believe THEY SAW SIMON'S CONDITION AS A HOPELESS CASE and so they weren't interested in prioritizing his care. In one meeting when I had simply 'had it' with the constant litany of 'I don't know's' in regard to how Simon would respond to surgery or adapt to more hands-on care, I blew up." I confronted them, stating angrily, "You guys remind me of the weatherman, you don't know anything about his condition but I am supposed to trust you!"

I recall a phone call to our insurance caseworker. I learned that our insurance company actually preferred we stay in the hospital. The caseworker said that if Simon was still struggling with apnea, it was medically necessary and insurable hospital care. We began to think our best option, at that point, was to stay in the hospital where little Simon had 24-hour medical attention despite their efforts to send us on home for him to die.

My only goal with Simon's care was that the doctors would TREAT HIS HEALTH ISSUES WITH THE SAME AGGRESSIVENESS as they would treat a child who didn't have his genetic condition. It too often felt like they were playing a shell game with our son's life-withholding information and treatment.

One time I was awakened at 4:40 a.m. by a nurse practitioner. Simon was awake, fussy and clearly irritated. She firmly asked me: "Do you want me to give him morphine?" I knew instinctively that giving a powerful narcotic to a tiny infant with severe heart problems was a bad, if not fatal, idea. I adamantly refused her recommendation. In hindsight he was likely fussy

because they weren't properly nourishing him. SIMON WAS ONLY RECEIVING "COMFORT FEEDS." Instead, I gently took my son in my strong arms and rested Simon on my chest. Our son calmed down immediately.

I will never forget Simon's nurse calling me as I was driving and about to get off at my exit for work. I immediately turned around onto the highway and headed back to the hospital. The time was now very short. Would our little warrior Simon wait for Daddy?

I arrived and held Simon peacefully in my arms as his father and protector. I could sense my son slipping away. I eventually felt the warmth of Simon's body dissipate and escape as I embraced him for the last time.

I am a Chapter Chair for S.O.F.T. (Support Organization For Trisomy). I have heard from many families dealing with similar circumstances that they WILL NOT LEAVE THEIR CHILD ALONE IN THE HOSPITAL and always monitored staff activity with the utmost caution. The irony is that both Sheryl and I did the exact same thing for Simon.

In the dad's group meetings I have attended with SOFT--as well as conversations with other dads across the country --I hear and feel the pain and heartache they experience trying to work and provide for their families and still spend hours in hospitals fighting for their children's lives. Do doctors really believe their medical acumen is so superior to a family's love? TOO MANY PHYSICIANS LACK COMPASSION FOR THEIR PATIENTS LIKE SIMON, and fail to connect with families on any level. And every person I talk to will tell you the fighting they must endure to get what is needed for their children to thrive and survive.

Futility Policies affect each and everyone us in the state of Kansas and across the country. The bottom line is, hospitals are making business decisions when the lives of our loved ones are at stake. So I ask you: why the medically-trained professionals ever thought they had the authority to take the decision out of the hands of parents.

In conclusion, if the hospitals are not going to be completely open and transparent concerning their policies, then we clearly need and ASK YOU, THE GOVERNMENT TO STEP IN AND PROTECT OUR PARENTAL RIGHTS. All parents should be fully informed of the treatment plan that will be followed as well as possible negative --even deadly-- implications such as overdosing medications, DNR's and comfort feeds. To this day I cannot believe they gave my son a medication that was contraindicated for his apnea. Neither Sheryl nor I ever approved a DNR, comfort feeds, or contraindicated medication-- all factors that shortened my beautiful son Simon's life. Please support Simon's Law.

Thank you.