

Simon's Law—Protecting Parental Rights in Missouri

On September 7, 2010, God blessed us with a precious son, Simon. Even with a bilateral cleft lip and weighing only 4 pounds, 3 ounces, he was our gift from God and absolutely perfect for our family.

On Simon's third day of life, he was diagnosed with Trisomy 18, also known as Edward's syndrome. For your reference, Down syndrome is Trisomy 21.

For too long, this condition has been considered a "lethal" anomaly and "incompatible with life" despite evidence of individuals with Edward's syndrome surviving for not only months and years, but even decades. Trisomy 18 children often require heart surgery to survive and we were scheduled to meet with a cardiac surgeon on December 6th.

Simon remained in the hospital and our lives revolved around him. Our family and friends spent many hours cuddling Simon and interacting with him. I continued pumping breast milk believing it was being fed to Simon. His cleft pallet made it difficult to him to nurse normally.

As Simon neared three months of age, we looked forward to surgery to repair his heart. Tragedy struck just days before the scheduled pre-surgery consult. On December 3, our son's oxygen levels were falling. Shockingly, we were told, "This is the end. Nothing can be done." We watched in disbelief as our child took his last breaths inside a hospital where he had been a patient for months and no "code blue" resuscitation was engaged.

We pleaded with the medical staff again and again, yet were told, "NOTHING can be done." We were losing Simon and where was our help? Where were those experts that we paid to save our son? No carts, no beeping monitors. The only people panicking were my husband and me. Absolutely nothing was done.

That morning at 10:45 AM, our sweet baby, Simon, died.

PAUSE

Our sorrow, as any parents', was unimaginable. Our agony was soon compounded when the other hospital called to confirm our upcoming consult appointment to fix Simon's heart and I had to tell them that my son was dead.

After Simon's death the nurses told us their hands had been tied. We were given indications that we should examine Simon's chart.

There we found the horrible truth; a do not resuscitate (DNR) order had been placed in Simon's medical file. Something we had no knowledge of and certainly had not given our consent. This explained why the staff stood around and did nothing. If Simon had been a typical three-month-old, in other words no defects, NICU staff would have done everything they could to save his life.

We also discovered that Simon had been getting only comfort feeds, not my breast milk. Comfort feeds, by definition is an insufficient amount of food for growth and development. Simon was being intentionally starved! As an example of that food denial, my husband Scott relayed that he had once been awakened at 4:40 a.m. by a nurse practitioner at the hospital when Simon was fussing and clearly irritated. She firmly asked, "Do you want me to give him morphine?" Scott knew instinctively that giving a powerful narcotic to a tiny infant with severe heart problems was a

bad, if not fatal, idea, so he adamantly refused her recommendation. In hindsight, Simon was likely fussy because he was very hungry from being denied sufficient nutrition in the "comfort" feed! Scott gently took Simon in his strong arms and rested him on his chest trying to comfort our son.

In spite of the fact that Scott had refused the administration of powerful drugs such as morphine, we discovered that on Simon's last day of life and once earlier that he had been given Adivan (lorazepam) a drug, which was contraindicated for his apnea. This was used to suppress his respiratory system. Simon's chart indicated declines in his oxygen levels. A pharmacist friend told us that he would not give this drug to an adult with apnea, much less an infant!

Unknown to us someone decided our son's life had no value. Without our knowledge or consent someone decided to withhold care, administer medications to hasten death and order a DNR to finalize Simon's life.

It is gut-wrenching to learn that all of this is legal and common for a physician to withhold care and place a DNR in a minor child's chart without parental knowledge or consent. Even worse, we discovered, it doesn't matter if the child is one day old or 17 years old. It doesn't matter if the child has a condition deemed "incompatible with life" or in a coma from a traumatic head injury. Any doctor can unilaterally issue a DNR order for a minor.

Unfortunately, Simon is not an isolated incident. The practice of unilateral issuance of DNR orders by physicians was verified in a recent survey by physicians and is recorded as truly happening in a film documentary called "Labeled." There are organizational chapters across the United States called Support Organization for Trisomy (SOFT) filled with parents who have lost minor children to unilateral DNRs and withholding of care.

Should it be legal to withhold procedures, medications, food and/or water to hasten the death of a child without parental knowledge or consent? Should it be legal to place a DNR in a child's medical chart without parental knowledge or consent?

Simon's Law says, "NO!"

I can't bring my son, Simon, back, but I want to make sure that no parent or guardian of a minor child is stripped of their parental rights in the determination of their child's life or death.

I want to make sure that no parent has to discover the horror that the very doctors they trusted with the life of their child betrayed them and secretly determined that their child should die.

In my opinion, no one loves a child more than his or her parents. I believe it is the parents' right to make informed medical decisions for their minor child.

The need for parental permission for DNR orders also extends to children without special needs who have experienced life-threatening accidents or disease.

Please protect our children and parental rights. Please stop the practice of issuing secret DNR's. If all children aren't protected, then all are at risk.

The name Simon means, "To be heard." Let Simon's message be heard! PLEASE make your state a Simon State.