

## Simon's Law—Protecting Parental Rights

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 to 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. From that day forward, his medical care diminished. 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 to pump 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 3 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.

Our sorrow, as any parents', was unimaginable. 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. "Comfort feeds" by definition is insufficient amount of food for growth and development. Simon was being intentionally starved!

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. Any doctor can unilaterally issue a DNR order for a minor.

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 or withdraw treatment necessary for life without parental knowledge or consent?

Simon's Law says, "NO!" Up to this present date, nine states agree, passing Simon's Law most often unanimously.

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.

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The need for parental notification for DNR orders and withholding of life-sustaining treatment and nutrition also extends to children without special needs who have experienced life-threatening accidents or disease.

Please protect parental rights, and our children's equal access to medical treatment. And please prevent the practice of issuing secret DNR's or secretly withdrawing treatment which goes against parent's explicit requests for medical treatment.

If ALL children aren't protected, then ALL are at risk!

The name Simon means, "To be heard". And I am here today on behalf of my son, Simon, and Simon's Law, in support of Emery and Elliot's Law because every child deserves the right to equal medical care and should not be discriminated against because they are premature or because they have been diagnosed with a disability or might end up with a disability.

Some of the most influential people in history have a disability, but it didn't stop them from making a difference with their lives, people like FDR, Beethoven, Steven Hawkins, Temple Grandin, Helen Keller just to name a few.

Every life is worth saving.

Emery and Elliot had a life to live and because they were premature and had a propensity for disability, they did not receive the lifesaving treatment that other babies would have received. Instead, they died an excruciatingly painful death suffocating as medical staff stood around and watched.

To say this is inhumane is an understatement. This kind of denial of medical treatment to certain groups of people appears to be increasing in our country and throughout the world. I am asking that all human beings be treated the same and have equal access to life saving medical treatment.

Please join me in support of Emery and Elliot's Law!

Thank you.