

Support Simon's Law

Saturday, 18 February 2017 10:29

GUEST COLUMN, Jeff Colyer, MD, Kansas Lieutenant Governor

http://www.leaderandtimes.com/index.php?option=com_content&view=article&id=28086%3Asupport-simons-law&catid=29%3Aopinion&Itemid=58

If you haven't heard of Simon's Law, it's time you do. The Kansas legislature knows it as Senate Bill 85, but even calling it by this technical name goes against the heart of the bill. You see, at the heart of this bill is the story of a little boy named Simon who left his parents and this earth at just 3 months of age.

Simon Crosier was born September of 2010 with a rare chromosomal syndrome known as Trisomy 18. Few children with Trisomy 18 survive their first year of life. In Simon's mother's book, *I Am Not a Syndrome—My Name is Simon*, Sheryl Crosier describes how life-sustaining care was withheld from her son, leading to his death in December of 2010. The injustice of his death lies in this fact: life-saving care was withheld from their without the parents' consent. Due to Simon's Trisomy 18, a Do Not Resuscitate order (DNR) was placed in Simon's medical file without his parents' knowledge or authorization.

Since the tragic loss of their son, the Crosiers have been on a mission to ensure children like Simon are not discriminated against because of their medical conditions. Simply stated, Simon's Law would make it so no healthcare professional could withhold or restrict life-sustaining measures or authorize a DNR on a minor without a parent's permission.

As a craniofacial surgeon, I have seen first-hand some of the most difficult situations a parent and their child can ever face. When I care for a patient who is unlikely to long survive, I am obligated to provide the best medical care and communicate realistically with parents.

Throughout my 23 years of practicing medicine, I have had to consider each situation independently. Each patient is a person, not a series of numbers and statistics. There have been times in my career when predictors indicated a certain outcome, yet the person's strength and ability beat the odds, allowing them to survive and thrive. It is my job to tell parents the facts and the odds and give them my opinion because they count on my education and experience to help them decide what choices to make. It is not my role to decide a patient is not worth treating because the odds are against them. In the end, as a doctor, I must respect that parents are best fit to make life and death decisions for their own children.

While this legislation sounds like common sense and should be easily approved, rarely is the legislative process simple. In the years to come, history will judge our society by how we treated the most vulnerable among us. Let us take a stand and protect children like Simon. Ask your legislators to vote yes on Senate Bill 85, then tell them Simon's story. Let us make sure his story is not repeated.





Senate weighs bill altering parental rights of medically fragile children

Updated February 16, 2017 01:43 pm By [Tim Carpenter](#)

<http://cjonline.com/news/local/2017-02-16/senate-weighs-bill-altering-parental-rights-medically-fragile-children>

Sheryl Crosier, of St. Louis, urged a Kansas Senate committee Thursday to endorse legislation requiring parental permission before do-not-resuscitate orders are attached by a physician to the medical file of a minor child. (Tim Carpenter/The Capital-Journal)

Sheryl Crosier's infant son died at 10:45 a.m. Dec. 3, 2010, a moment marking the beginning of her life as an advocate for laws preventing doctors from imposing do-not-resuscitate orders on children without consent of the parent.

On behalf of Simon and families that could endure similar heartbreak, Crosier made a case Thursday to the Senate Federal and State Affairs Committee for passage of a bill compelling Kansas medical facilities to disclose policies related to end-of-life care and to prohibit implementation of DNR orders without parental permission.

Senate Bill 85 was opposed by the Kansas Hospital Association and other medical providers. Support for the measure — a similar bill passed the Senate last session — came from Lt. Gov. Jeff Colyer, the Disability Rights Center of Kansas, Kansans for Life and the Kansas Catholic Conference.

Crosier, of St. Louis, said Simon was diagnosed three days after birth with Trisomy 18, a rare chromosomal syndrome also known as Edward's syndrome.

"We wanted Simon to have every opportunity to thrive and survive," Crosier said. "However, some medical professionals thought differently. When Simon's oxygen saturation levels began to fall, we were told this is the end. Nothing could be done. Simon drew his last breaths. I asked again what could be done and was told, 'Nothing.'"

She said a hospital physician had attached a DNR order to Simon's chart without consent. She belatedly discovered the hospital had a "futility" policy, which allowed physicians to withdraw treatment deemed futile. For example, the boy was given "comfort" food intended not to nourish.

After his death, Crosier began to promote Simon's Law, which would make transparent so-

called futility policies and require consent for DNRs regarding minor children with life-threatening conditions.

“It’s a protection of parental rights and protects a child’s human rights,” she said.

Deborah Stern, senior vice president of clinical services and general counsel with the Kansas Hospital Association, said the Senate bill applicable to care of patients under the age of 18 was drafted despite lack of evidence issues raised by Crosier had arisen in any Kansas hospital or medical care facility.

Delivery of compassionate and empathetic care for patients doesn’t require a piece of legislation, said Emily Riegel, medical director of pediatric palliative care at the University of Kansas Health System. The bill, she said, uses a blunt instrument of statute to disrupt tender conversations and difficult decisions between a family and the physician.

“This bill, in its very existence, questions the motives and intentions of extensively trained, highly skilled, profoundly compassionate physicians, nurses, social workers and chaplains, and in doing so, drives a wedge between these providers and families,” Riegel said.

Colyer, a craniofacial surgeon and the Republican lieutenant governor, endorsed the Senate bill. He said the measure was necessary to counter a system of medical care that allowed someone other than parents decide whether a child’s life held value.

“When I deal with a patient and the family where it is unlikely the child will survive very long, I am obligated to provide the best medical care, provide excellent, realistic communication with parents, and to respect their wishes,” Colyer said. “Part of being human is that we will not all make the same decision in the same circumstances. In the end, I must respect that the parents are best to make life-and-death decisions for their children.”

Brenda Spurlock, a Topeka mother of eight children, said her daughter, Tatum, was prenatally diagnosed with Trisomy 18 — the same syndrome that afflicted Simon Crosier. Taken into consideration with several other medical realities, Tatum was given a fatal diagnosis prior to birth. She recently celebrated her ninth birthday.

“Tatum has far surpassed any of the prenatal and postnatal prognoses that were given to us,” Spurlock said. “Every parent of a medically fragile child should be aware of the choice to sign a DNR for their child. 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.”
