

Lt. Governor Colyer Testimony on SB 85, Simon's Law

Chairman LaTurner and Members of the Committee-

Thank you for allowing me to submit testimony in the strongest possible support of SB 85, more commonly known as Simon's Law.

Little Simon Crosier blessed his family with a love that has long surpassed his few months on this earth. Born September 7th, 2010 with a rare chromosomal syndrome known as Trisomy 18, the Crosiers loved their baby boy. In the book, **I Am Not a Syndrome—My Name is Simon**, Sheryl Crosier describes how life-sustaining care, without their consent, was withheld from their son resulting in his death on December 3rd, 2010. Apparently, a Do Not Resuscitate Order (DNR) was placed in Simon's medical file without their knowledge or authorization.

Since the tragic loss of their son, the Crosiers are on a mission to ensure children like Simon are not discriminated against because of their medical conditions. Mr. Chairman, I wish to join in their fight.

As a craniofacial surgeon, I have seen first-hand some of the most difficult situations a parent and their child have had to face. We should always look for hope and life. For example, not so many years ago, children born with Aperts Syndrome, a deformity in which a child is born with his or her skull fused, were considered "non-survivable." Today I have some of these special patients who have graduated from college, married their sweetheart, and live a life of meaning. One of the reasons new options exist is because many parents, through many years, have fought to give their children another chance at life, no matter the odds.

Today a number of parents with children diagnosed with severe deformities have described similar circumstances. They believe their children were denied medical care because someone, other than the parents, decided their children's lives had questionable "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. 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. But the point is, we are all human, and every human life is precious and has value.

Losing a child is probably the most searing thing that can happen to any parent. But those few moments of breath or weeks in the ICU, are sometimes the most life affirming times in any family's life. If the family is overruled in a matter of life or death, especially without their consent, it breeds suspicion and doubts about health care and basic values. When parents are

fully involved in these final decisions, it makes closure possible, memories more beautiful, a child's meaning more remarkable, and healthcare better for everyone.

Throughout my 20 years of practicing medicine, I have had to take each and every situation as its own, with completely different circumstances than the last or the next. Each case is a person, not a series of numbers and statistics. There have been times in my career when I have predicted a certain outcome and have been surprised by the person's strength and ability to survive and thrive. It is my job, however, 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. But it should be the parent that decides their child's fate. It is not my role to decide a patient is not worth treating because the odds are against them.

I, along with medical organizations like the American College of Pediatricians, and individual physicians and nurses am urging the 2017 Kansas Legislature to approve Simon's Law. Having passed the Kansas Senate in 2016 on a vote of 37-3, the measure failed to gain passage in the House due to some last-minute maneuvering.

SB 85 calls for parental consent before

- life-sustaining care is withheld from a child, or
- a DNR is placed in a child's medical file.

While this legislation sounds like common sense and should be easily approved, rarely is the legislative process simple. That being said, I strongly believe this legislation should be approved this year. In the years to come, history will judge our society by how we have treated the most vulnerable among us. Let's take a stand and protect children like Simon.

Once again, thank you very much for your time and the opportunity to address the committee.

Respectfully,

Jeff Colyer, MD

Lt. Governor of the State of Kansas