

**To: Chairman John Barker
Kansas House – Committee on Federal and State Affairs
Room S-346, Topeka Capitol Building**

From: Brian Carter, MD, Neonatologist

Date: March 21, 2017

RE: Testimony on HB 2307 (Simon's Law)

Evy Kristine and Simon deserve more than a Law

Addressing the needs of parents who face the tragic realities of losing a child is a difficult and delicate matter for the parents, physician, nurse, social worker, chaplain, and patient advocate. It is a matter of trust and respect that should be handled with sensitivity and skill. It is not a matter for the legislature. It is not a matter for the courts. It requires a close and intimate working relationship; one that is built on trust and respect. It is a matter of compassion, of duty, of care, of commitment to serve and listen and in making shared health care decisions.



Children who arrive in this world who are literally hanging on to the edges of life deserve the best we have and the best we have is not reflected in the blunt instrument of the law, or in the cold proceedings of a court room.

As a neonatologist for over 30 years, the last five at Children's Mercy, I have experienced the anguish of hundreds of parents facing these tragic circumstances. I have written extensively and trained professionals in the skills necessary to navigate these complex and inescapable cases. In 2013, I co-authored an article entitled **The Story of Evy Kristine: Why Were They in Such a Hurry to See Her Die?**ⁱ appearing in the American Journal of Hospice and Palliative Medicine chronicling one family's story.

Evy Kristine, the child written about by me and my colleagues in 2013, and Simon, the child whose life and memory prompted this bill you now deliberate, deserve better from us to help parents navigate this journey. They deserve more from us as clinicians, as administrators, and as public policy makers.

What happened to Evy Kristine's and Simon's parents insofar as how the clinical interactions occurred is preventable, but it won't be a law that corrects errors in communication. My colleagues and I

"When Evy Kristine died there was a hailstorm, it was as if the Angels cried. I had sat with Evy Kristine for a long while, so I took a nap. When I woke up some time passed before she died. She was so beautiful. I was the one who gave her her name."

~ Einar, Evy Kristine's big brother

commit to you that we will not relent in our efforts to ensure that every child whose care we are entrusted with and every parent whose heart we hold next to our own is treated with the utmost respect and dignity. These families deserve our best, and legislation – which cannot deliberate special circumstances and accommodate intricate medical situations with families – will fail to produce the ends desired. We must respect the potentially individual circumstances and unique aspects of every complex case that can change as dramatically as the baby's condition changes. We don't need legislation that puts doctors at odds with parents about what treatments are appropriate or effective. When physicians and families have struggled together for hours or days to arrive at life's most difficult choice – to forego or withdraw life sustaining medical treatments for a child – no added value comes with complicated verbiage and a requirement that parents then must sign an order of such a lasting duration. Indeed, I have had families recoil from the thought of having to sign such an order, as it makes them bear the burden of ordering the end of their much loved child's life. Some have clearly stated that they see in such a process their own moral culpability. Physicians, too, may feel similar angst, but bear the professional responsibility to work with families and both write and implement such orders.

The decisions we are talking about are shared in process, and mutually affirmed by the clinical team and the family. In the worst of situations, they may come during a period of rapidly escalating circumstances and moments of high anxiety, but they are not unilateral. Transparency is essential. Parents deserve providers with more compassionate skills, supported by more sensitive training, which cannot be accomplished with a statute.

Evy and Simon deserve better from all of us. However well-intentioned this measure is, it does not serve them well. I have dedicated my practice and my life to achieve improved communication and decision-making skills in healthcare. I can assure you that neither I nor my colleagues, will relent until a fair and compassionate measure is accomplished.

We in the field of perinatal, neonatal, and pediatric care commit to take up the mantle of these complex and deserving cases and commit to addresses the needs these stories portray. We commit to build a better legacy with a higher standard to yield a greater sense of trust, than any law or regulation or ruling could ever imagine. We commit to improve our practice and knowledge that finds a better way to take care of Evy and Simon and their parents in the least burdensome and most effective manner.

Brian S. Carter, MD
Professor of Pediatrics, UMKC School of Medicine
Division of Neonatology and Center for Bioethics

ⁱ Berg, Paulsen, and Carter. *Am J Hosp Palliat Care* 2013 30: 406