

SB 85- "Simon's Law"
Federal and State Affairs Committee
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Testimony by Emily Riegel, MD
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My name is Emily Riegel, MD, and I am the Medical Director of Pediatric Palliative Care at the University of Kansas Health System, and Medical Director for Carousel Pediatric Hospice and Palliative Care. I am here today to share my concerns about SB 85, "Simon's Law." These concerns are my own, and are based on 10 years of medical practice, including training in pediatric medicine, internal medicine, and hospice and palliative medicine. My qualifications to speak to you do not simply come from my training and professional experience, however, and this also matters to me on a deeply personal level. I am not providing this testimony on behalf of the University of Kansas Health System, the University of Kansas School of Medicine, or other entities of the University of Kansas, nor any entities related to Carousel or Kansas City Hospice and Palliative Care.

My background in completing a dual residency in pediatrics and internal medicine, then pursuing fellowship training in hospice and palliative medicine means that I have had the honor of working with patients of all ages, and their families, during what are likely the darkest moments of their lives. Facing the serious illness or impending death of a loved one is difficult in any circumstance, but facing this with a baby or child is almost unbearable to even think about. With this in mind, and knowing there is nothing more sacred to a physician than the trust of a patient or their family, I strive to continuously provide, and watch my colleagues strive to continuously provide, the most compassionate and empathetic care for our patients. We do so *without* needing a piece of legislation to tell us this.

The concerns that I have related to this bill are directly related with the ways in which this type of legislation would directly affect health care providers and families alike when facing these most delicate and fragile of scenarios in which we are often providing care to the most delicate and fragile of children. This legislation inserts, uniformly to all of those sacred conversations and decisions, the blunt instrument of the law in a way that could severely interfere with and disrupt these tender conversations and difficult decisions between a family and the physician.

My concerns that specifically apply to the language included in SB 85 include: Requirement of **written permission** of at least one parent or legal guardian prior to withholding, withdrawing, or placing restrictions on life-sustaining measures for any patient, resident or ward under 18 years of age, and by extension, Subsection (f), which **disallows** the withholding, withdrawing, or restricting of any life-sustaining measures as well as disallows any do-not-resuscitate, or similar, orders to be instituted **if** one of the parents institutes court proceedings related to these orders until such proceedings can be completed and decision rendered.

On first glance this language seems reasonable and appropriate and a standard to which all clinicians involved in these kinds of situations would strive. However, the practice of medicine, especially in the care of our most fragile and vulnerable, is not always straightforward. This is why what seems like a straightforward rule that a document must be signed could actually be the thing that creates the most difficulty and distress for a family.

In my practice, parents have told me that the most difficult part of the decision-making and the situation they have been in came when they "had to sign a DNR." In Kansas, when a family decides to have a do not resuscitate order for their child *outside* the hospital (often done for children with terminal diagnoses who are receiving palliative or hospice care at home), they must sign what is called an "outside the hospital" or "community" DNR. I have watched as parents, with whom we have had very clear conversations and who have struggled in making this difficult decision but approach it selflessly and with love and mercy, take a pen into their hand and stare at that piece of paper. The struggle of the emotional weight of the decision to allow their child a natural death, is written on their faces and in their tears. Parents have told me that although they know they are making the best decision for their child, and they know this is a way to prevent suffering, they still feel like they are doing something wrong. I have had a parent compare it to feeling like signing a death warrant for their child. I have had parents refuse to sign it, unable to bear that weight. The law, though, requires this when a child is expected to die at home, and it is understandable based on the circumstances of the home settings and potential issues with the death of a child at home.

When a child may die in the hospital, though, the current requirements are different. In the hospital setting, after a family reaches this decision, the clinicians place an order for "do not attempt resuscitation" into the electronic medical

record; paper forms are not required for this. The clinician must then document the conversation that was had with parents, and are encouraged to be detailed in their documentation of the conversation and factors related to the decision-making. I have had parents ask me “what do I need to sign,” and when I tell them our process does not require them to sign anything, I have yet to see anything other than relief wash across their faces. A relief at knowing that the deepest wound they have ever had cut into their heart is not going to be deepened because of a policy requiring them to put their name on a DNR order. In creating legislation that would require even in-hospital DNR orders to be signed by a parent, lawmakers are part and parcel in adding to the heartbreak felt by families.

This is not to say that physicians should have the ability to make decisions about the child’s ongoing medical care without the involvement of the parents. However, this is, quite plainly *already* the standard of practice required by the systems in which we work. There is nothing to suggest otherwise about the practice of medical care for children in the state of Kansas in the past, and certainly nothing to predict it would happen in the future.

When I read these, and envision these rules being applied to clinical situations, my main concern is that they lead to an increase in potential suffering – for the patient, as well as for the parents – and as we all know, the first obligation of any physician is “*primum non nocere*.” First, do no harm. In these instances, the potential for aggressive medical interventions, such as endotracheal intubation, cardiac resuscitation with chest compressions, electrical shocks, placement of large bore intravenous lines, or sometimes lines driven through the skin and into the cortex of the child’s bones, to administer medications in rapid sequence, insertion of tubes into the space between the ribs and the lungs or into the delicate sac around the heart, to cause harm in terms of potential pain and suffering for the child is high. Legislation such as this creates a scenario in which a parent’s understandable inner conflict could place a child at risk of undergoing this kind of aggressive resuscitation, or a prolonged course of care in the hospital that is essentially a drawn out version of this. No parent, and no child should suffer this fate because of a piece of unnecessary legislation.

Earlier in this testimony, I mentioned personal reasons that compel me to testify to this bill, which I will share with you now. When I was 6 years old, I became a big sister for the second time. My brother, Benjamin, was born via emergent c-section, a few weeks ahead of schedule. My mother had spent the prior 5 weeks admitted to the hospital, on strict bedrest, due to complications with the pregnancy. Benjamin was born a very sick baby due to congenital diaphragmatic hernia, which prevents the baby’s heart and lungs from being able to properly develop. Benjamin’s case was severe, and he was born right at that time that surgeons and neonatologists were just beginning to have success in treating these babies. Unfortunately, Benjamin had complications from the time he was born and after three days in the NICU, with ever-increasing needs for life support, and decreasing chances that he would survive, the neonatologists had a heartbreaking conversation with our parents. After that conversation, and after spending time weighing the decision, our parents told the team they did not want Benjamin to continue to suffer. They asked to have time holding their son, without the tubes and lines and machines hooked to him. My mother held him as he took his few and only breaths and gently died. Thirty-two years later, Benjamin’s birth and death remains the single most life-altering event that has occurred in our family. I watched my parents grieve, I watched them struggle with the weight of guilt they felt in making that decision even though they had all of the information they needed and knew they were doing the most loving thing for Benjamin. It still nearly broke them and nearly broke our family – but my mom has always said, and consistently expresses the appreciation she has for the doctors who talked to them and supported them during that time. Ask me why I am committed to providing excellent care to patients and families, or how I can speak to the importance of allowing physicians to practice in the best and most compassionate ways without the laws of unintended consequence tampering with these relationships. One word: Benjamin.

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. Rather than allowing the conversations and decisions to take place under the assumption of trust, it casts a shadow of doubt into an already incredibly difficult situation. It assumes bad intent of the healthcare team, rather than assuming that we are all there for the same reason: to provide the best and most compassionate care, without infliction of undue suffering, to ALL patients: regardless of age, gender, race, religion, or ability. Thus, the grounds for creating a piece of legislation such as this seems unnecessary at best, and at worst, politically motivated with an intention to insert politics into the sacred doctor-patient relationship. The physicians and families of Kansas deserve better.

Sincerely,



Emily Riegel, MD

