

HB2307 Testimony
House Committee - Federal and State Affairs
March 21, 2017

Chairman Barker and Members of the Committee:

Clearly no parent should ever learn that her child has a DNR order issued without her knowledge, her involvement, or her participation in shared decision making.

The need for involving parents in this critical decision is a fundamental moral obligation, a “duty of care” as it is called in medicine. It is a tenet of shared decision making and it is required in order to act in the “best interest of the child.”

The failure to do so is a violation of the standard of care.

None of this is in dispute.

Parents and guardians have that same moral obligation to act in the best interest of a child. Parents should be afforded the opportunities to seek all appropriate medical treatments and interventions for a child who faces life threatening illness. But parents should also be protected from having to sign a “permission” slips allowing their child to die. That’s a role that the physician should protect them from.

If we could get to the common ground of what Parents and Medical professionals share in their duties to care for fragile children, we would be speaking in favor of this measure rather than in opposition. In fact, we would like to be coming before you no in favor of this bill but we have not yet met with all the stakeholders to gather their perspectives. We can get there. We have a date set. Action on this matter deserves that thoughtful and deliberate consideration. If we meet - as parents, medical providers and as policy makers we can arrive at language that all can support. I know that to be true because I believe in the integrity of the physicians who care for fragile children in the finest pediatric and neonatal units in this state. The invitation is on the table. A number of us have already agreed to meet on June 15. Adopting a resolution in that meeting would put us on a path to creating language that all parties could support.

For some reason Simon’s Law has become about something other than ensuring that parents are involved in the intimate and difficult decisions that they make with the support and guidance of medical professionals. This has become about the rights of parents to demand treatments that belong in the realm of physician practice. They belong to physicians because they require knowledge and skills that parents do not possess. They belong to physicians to ensure that medical care is appropriately provided and that parents are involved in the decision making that best serves their child’s interest. Unfortunately this proposed measure has morphed into some challenge that places government, the state of Kansas in this case, intervening (and some would argue interfering) in the intimate and complex and yes, sacred conversations that have to take place between parents and doctors when a child faces life threatening illness.

In *Cruzan v Missouri Dept of Health* in 1990, the Supreme Court of the US determined that Americans have a constitutional right to refuse treatment. That decision however also made it clear that that constitutional right does not include the right to physician assisted death. Nor does it, by extension, include the right for individuals who are acting as agents or guardians on behalf of another to demand treatments that offer no medical benefit or may pose additional risks or harms. That includes parents and guardians acting in the best interest of a child.

Parents, other than those who are medically trained to do so, are not in a position or qualified to make determinations about the effectiveness of medical interventions and medical treatments.

In fact, existing federal law supports the physician in exercising “reasonable medical judgment,” particularly in the cases of infants when the provision of such treatment would “not be effective in ameliorating or correcting all of the infant’s life-threatening conditions.” Protecting that medical integrity, also protects parents from having to grant “permission” to allow for the tragic death of their child.

There is a path forward. It is a reasonable approach to resolve the questions and issues impacting parents, physicians and policy makers. It is a path that could lead to language that all parties could agree to. The path is simple.

Let us meet and work together to adopt language. If we could but trust that parents like Sheryl Crosier, Simon’s Mom, among others, and physicians like Brian Carter, Emily Riegel, Karin Porter-Williamson, John Yeast, Sandra Stites, representing neonatology, maternal and child health, gynecology, pediatrics, palliative care could sit down with representatives from this body, then we could craft language and resolve to protect the best interest of vulnerable children.

By suggesting in this proposed law that the respective interests of parents and physicians are irreconcilably at odds, violates the covenant of the doctor patient relationship. It engenders suspicion and erodes trust. That is not what we value in health care in Kansas. It is not what Kansans believe about their doctors. And it serves no good end.

Please, amend this legislation allowing for our meeting of parents, physicians and policymakers to take place, so we may return to this body with language that we can all support and is truly in the best interest of the children we serve to protect.

Thank you for your consideration.

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