

PROPONENT, HB 2307, SIMON'S LAW

To: Kansas House Federal & State Affairs Committee

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I am an American Board of Pediatrics certified neonatologist and Professor of Pediatrics in the Division of Neonatal-Perinatal Medicine at the University of North Carolina School of Medicine. I have been in neonatal practice for the last 20 years, have cared for numerous **infants and families with challenging and potentially life limiting diagnoses**, and have spent the last ten years advocating for families internationally with children with potentially life limiting conditions, especially trisomy 13 and 18.

I write to offer my **unequivocal support for Simon's Law**. Simon's Law is proposed to prohibit the practice of a hospital placing a unilateral DNAR order on a child's chart. **"A unilateral do not attempt resuscitation (DNAR) order is written by a physician without permission** or assent from the patient or the patient's surrogate decision-maker. Potential justifications for the use of DNAR orders in pediatrics include the belief that attempted resuscitation offers no benefit to the patient or that the burdens would far outweigh the potential benefits. Another consideration is the patient's right to mercy, not to be made to undergo potentially painful interventions very unlikely to benefit the patient, and the physician's parallel obligation not to perform such interventions. Unilateral DNAR orders might be motivated in part by the moral distress caregivers sometimes experience when feeling forced by parents to participate in interventions that they believe are useless or cruel."¹

In my twenty years as a practicing neonatologist it has never been my experience, or any of my colleagues, that a unilateral DNAR order was required in the care of a sick infant. In my opinion it would only be reasonable to consider such an order when there is absolute certainty from multiple members of the medical team that "there would clearly be no benefit to the patient of CPR; that is, death is imminent with or without it."¹ **When a medical team partners with parents and families in trying to determine the best course of care for a child, it is extremely rare that a point in care is reached where the medical team believes the situation is without physiologic hope but the parents do not.** In these rare cases, the medical team has the option to seek intervention on behalf of the well-being of the child (withdrawing what are felt to be hopeless and potentially cruel and painful interventions) through the courts. In cases where the medical team feels that medical intervention is warranted to best serve a child, but the parents refuse to consent, as occurs in the case of a baby with Jehovah's Witness parents who requires a blood transfusion, the medical team will seek a court order to support such intervention. In such circumstances the medical team does not unilaterally decide that a transfusion will be administered unless it is a dire emergency. In the case of ending a child's life, the same standards at least should apply. It is unconscionable that a medical team would unilaterally execute a DNAR order without a court order.

As a physician it is generally my belief that government has no place in the doctor patient relationship. **However, the increasing discussion and comfort of some physicians with an expanded use of unilateral DNAR in the case of minor patients, justifies such legal action.** There already exists a path for the formal adjudication of the rare cases in which the medical team believes a patient is physiologically

hopeless but the parents disagree. It is the court system. **The worrisome aspect of the unilateral DNAR discussion is the willingness of some physicians to circumvent the infant's and parents' right to legal proceedings regarding disagreement on an issue of life or death.** Additionally, this decision increasingly includes a willingness of some physicians to consider quality of life as a key element in their decision making process. While a life with a disability, even multiple severe disabilities, may be inconceivable to some, there are many with severe disabilities who believe they have rewarding lives, as do their families. A medical team using its subjective prediction of future quality of life as criteria to make life and death decisions, forcing that determination on a family via unilateral DNAR, is a tyrannical enforcement of prejudice towards children with disabilities.

The case which prompted Simon's Law legislation is a prime example of such bias. Infants diagnosed with Trisomy 13 and 18 manifest a range of medical complications. Generally these infants experience severe developmental and motor delays in addition to their medical challenges. They do have shortened life spans and for decades it has been the medical party line that such infants possess a "lethal" or "fatal" condition. Studies over the years report survivals at one year of 5%. As a result, in an age of prenatal diagnosis, mothers are actively offered termination for their pregnancy or, if desiring a livebirth, encouraged to limit support for their children after birth. When parents express a desire for active medical intervention for their infant, many parents have been discouraged or denied intervention. In some cases infants receiving initial care have had care limited or withdrawn without knowledge of the family. For this particular group of patients, unilateral DNAR has been a policy, written or unwritten, for some time.

As regards Trisomy 13 and 18, the most complete analysis we have for survival of such babies in the United States was recently published. This data suggests survivals are higher for such infants overall, 10-15%, and that the rates are variable based on the location of birth. In Georgia for example, survival at one year is 25% for trisomy 13 and 18 infants. In addition, in all states, the survival for babies alive at 1 month is 40% at 1 year. Further, if a Trisomy 13 or 18 infant is alive at one year, their survival to 5 years is 80%.² **We treat many with a variety of cancers with worse survivals but never tell the patient their cancer, at diagnosis, is lethal.** We offer hope, and over time, if hope is unwarranted for survival, we discuss and reach understandings with families regarding prognosis and interventions to be made. While the trisomy 13 and 18 are life limiting, they are not lethal in the respect in which they are often portrayed. Routinely parents are told that their child, if they survive to be born, will be born dead, or only live minutes or perhaps a few hours. The anecdotes reported by parents whose children are prenatally diagnosed with these conditions are horrifying.

So what is going on here? There are significant variations in the care offered such infants. In some states and regions survival is longer than others. Presumably a result of the care offered, larger percentages of trisomy babies survive longer in some states than others. Approximately 50% of trisomy babies die within the first month of life. Some infant's with Trisomy 13 and 18 succumb to severe medical conditions which cause death in the first month of life. Many though do not have such conditions but based on "lethal" prenatal counseling, "lethal" decisions are made to withhold basic care, including feeding, for some trisomy infants after birth. Early death then ensues. The bottom line is that by the

medical establishment **labelling trisomy 13 and 18 as “lethal”, we have created a self-fulfilling prophecy.** If a doctor says something is “lethal”, and care is limited that would be offered to a child with a normal number of chromosomes, it becomes lethal.

Simon’s Law is designed to guarantee parents their proper role in participating in healthcare decisions for their vulnerable children. In a perfect world this would not be necessary but it has become necessary as a result of an increasing willingness for hospitals and physicians to consider unilateral DNAR. **In a recent study of neonatologists in the United States, in three different vignettes, 25-76% of neonatologists felt it was justified to place a unilateral DNAR on a patient’s chart.**³ The intent of Simon’s Law is not to require hospitals or physicians to endlessly support cruel or unrealistic expectations. In those rare situations where there is a lack of agreement between parents and the medical team, and the medical team believes ongoing care is hopeless and inhumane, the option to bring such cases for court review already exists. It is shocking that the neonatal community in the United States has reached a point where a significant number of providers feel it is justified to place a unilateral DNAR order on a child’s chart, based on a neurologic prognosis which parents are perfectly willing to accept, but the medical team does not. It is unconscionable that hospitals in the United States may be following the lead of other nations like the United Kingdom in developing futility pathways, like the Liverpool Care Pathway, that deny patients medical care without consent from family members.

As a physician regularly caring for severely ill infants it is my sincere hope that Simon’s Law will pass. **The only physicians and hospitals that would be impacted by this legislation are those employing unilateral DNAR.** An inclination to override the voice of families by a medical care system that seems increasingly comfortable with its inhabitants employing subjective judgments in determining whether a patient lives or dies should have us all hoping Simon’s Law passes.

Very respectfully,



Martin J McCaffrey, MD, CAPT USN (Ret)
Director, Perinatal Quality Collaborative of North Carolina
Professor of Pediatrics, Department of Pediatrics
Division of Neonatal-Perinatal Medicine
UNC School of Medicine, Chapel Hill, North Carolina
(919) 619-1422

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