

Proponent, SB 437 SIMON'S LAW

March 3, 2016

Senate Public Health & Welfare Committee

Chairman O'Donnell and members,

Today you are learning about very distressing situations of denial of life-sustaining treatment to children, sometimes with their **parents present at the bedside-- yet unaware of the true extent of the threat** to their beloved offspring.

And clearly, these are instances reflecting **medical discrimination toward children with special needs**. There has been a short film produced about this bias, called "Labeled."

These "horror stories" were shared after Simon's mom, conferee Sheryl Crosier, began a crusade (and wrote a book) to protect other parents from the tragedy she and her husband, Scott, experienced five years ago.

What we have compiled is a packet of testimony, the majority coming from **families who found that DNRs had been placed in the medical charts of their special needs children**, without their knowledge or consent. These are compelling stories. Some of the children died --as did Simon--and a few escaped death. Some highlights:

Pg.1- Simon's story: in which a baby with **Trisomy 18** dies when a DNR without parental consultation was placed in his chart.

Pg.3- A mom mourns her daughter with **Trisomy 18** who lived to age 19 only to die due to a secret DNR effectuated during hospitalization for pneumonia.

Pg.5- An ER doctor tells of how the medical world had been trying to kill her **Trisomy 13** daughter since before she was born.

Pg.7- A pediatrician aligned with S.O.F.T. [Support Organization for Families with Trisomy 13, 18 and Related Disorders] believes sections (b) & (d) of Simon's Law can produce "an environment that allows medical decisions to be made in an ethical and transparent way."

Pg.9- A mom describes how her now-7-yr old son is living with an unrepaired heart due to a dismissive assessment that his **Trisomy 18** condition was "incompatible with life."

Pg.11- A mom tells of a newborn being scheduled for heart surgery UNTIL a diagnosis of **Trisomy 18**, after which the infant was denied sustenance and sent home too early.

Pg.13- A mom discusses her now-22-months-old daughter, born with **anencephaly**, who was not properly treated, overdosed and given a DNR order in secret.

Pg.15- A mom tells of discovering that a secret DNR was placed in the medical files of her 14-yr-old daughter with **Trisomy 18**; the mom reports she continually has to argue with medical personnel that her daughter is to receive full resuscitation.

Pg.17- A mom insists on the parental right to decide about a DNR, and worries about her youngest daughter with **Trisomy 18**.

Pg.19- A nurse recalls the discrimination she fought to get proper care for her daughter born with a heart problem and **Down Syndrome**, and how it set her on a career of caring for the medically vulnerable.

Pg.21- A doctor has become involved in verifying medical charts that had secret DNRs placed in them, after it happened to her daughter with a **rare chromosomal diagnosis**.

Pg.23- A professional researcher with direct contact with families with children with **Trisomy 18** urges that medical needs should *not* be dictated by a diagnosis and hospital policies be reviewed to eliminate this practice around the country.

Pg. 25- The editor of Sheryl Crosier's book, *I'm Not a Syndrome – My Name is Simon*, tells of numerous interviews verifying the lack of urgency attached to saving Simon's precarious existence by some physicians responsible for his care plan.

NOTE: The need for parental permission for DNRs also **extends to children without special needs** who have experienced life-threatening accidents or disease.

We offer a few amendments (attached) intended to help clearly distinguish between

1. **truly medical judgments**- that a treatment is futile because in reasonable medical judgment it will not work to preserve life –or- medically inappropriate because the risk of causing death is greater than the chance of saving it,
- VS
2. **value judgments**- that a child's life is not worth living which doctors should not be able to impose on the child's parents.

Here's an analogy.

Suppose there were a fire in this building, and when the firefighters arrived, you, Mr. Chairman, tried to dictate to the firefighters where they should put their hoses and how they should go about rescuing trapped people. Instead, it would be proper to defer to the professional judgment of trained firefighters about how best to fight fires, or even whether a fire could successfully be fought. But suppose, instead, that when the firefighters arrived they took a look at the building and said, "We think this is an ugly building. It ought to burn down. We're not going to put out the fire."

Firefighters are entitled to their architectural opinions like anyone else. But their role as firefighters is not to decide which buildings are worth saving and which are not – their job is to do the best they can to save buildings threatened by fire, and the people in them.

In the same way, we should, and **this bill does, defer to physicians' reasonable medical judgment** about whether particular treatments can or cannot be effective in preserving particular children's lives. But, while **medical personnel may have opinions about what conditions make life worth – or not worth-- living**, or what side effects should or should not be endured in order to preserve a life; that is not their role as health care providers. Their role is to do what they can to save lives and improve health.

We realize some health care personnel say that treats them as technicians, and that as professionals they have ethical views that would be violated if they are forced to treat a child **they believe would be better off dead**. We respect the conscience rights of health care personnel. But **we have to balance those rights against the rights of their patients who are at their mercy – who depend on them for their very lives**.

Another consideration:

The state gives a monopoly to the health care professions through licensure laws. We would not say that a doctor who claimed his conscience prevented him from saving the lives of racial minorities should be permitted to practice racial discrimination in choosing which of his patients to save and which to let die.

In the same way, **we must not allow medical personnel, no matter how sincere their views** that certain conditions or disabilities make it better **to hasten the death of children**, to discriminate on the basis of disability or **so-called "quality of life."**

We appreciate your reflection about these grave matters. I stand for questions.

Kathy Ostrowski

Kansans for Life Legislative Director

**Kansans for Life suggests these amendments
to improve Simon's Law, SB 437:**

1. On lines 10-11, strike "involving life-sustaining or non-beneficial treatment" and insert "involving life-sustaining treatment, including any policies related to health care deemed futile, inappropriate, or non-beneficial,".

2. Following line 21 insert the following:

(e) Subject to subsection (f), the requirement of written permission in subsections (c) and (d) shall not apply if providing resuscitation or the procedure, food, medication or nutrition would be:

(i) futile- because in reasonable medical judgment withholding it would not cause or hasten the death of the patient; or

(ii) medically inappropriate- because in reasonable medical judgment providing it to the patient would create a greater risk of causing or hastening the death of the patient than would withholding it.

(f) Subsection (e) may be implemented so long as a reasonably diligent effort has been made to contact at least one parent or legal guardian, who if contacted has been informed of the planned withholding or do-not-resuscitate order, and cooperation has been provided to efforts by a parent or guardian to obtain other medical opinions or a transfer of care to a provider selected by the parent or guardian, if so requested.

3. On line 22, strike "(e)" and insert "(g)".

4. In lines 23- 24, strike "life-sustaining or non-beneficial treatment" and insert "life-sustaining treatment, including any policies related to health care deemed futile, inappropriate, or non-beneficial,"

5. Following line 25 insert the following:

(h) For purposes of this act, procedures, food, medication or nutrition are "life-sustaining" if, in reasonable medical judgment, their withdrawal or withholding would result in or hasten the death of the patient.

(i) For purposes of this act, "reasonable medical judgment" means a medical judgment that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved.
