

Proponent, SB 85 SIMON'S LAW

February 16, 2017

Senate Federal & State Affairs Committee.
Chairman LaTurner and committee 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.

The traditional presumption in favor of life is in jeopardy. While we respect the expertise of health care personnel, there are far too many victims of value-judgment-based unilateral DNR placements to ignore the issue. A poll of pediatricians last year showed that, depending on the scenario, as many as 75% believed they had the right to issue DNRs without notice or permission by parents. [Murray PD, Esserman D, and Mercurio MR. In what circumstances will a neonatologist decide a patient is not a resuscitation candidate? J Med Ethics. 2016 Mar 17]

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

In our attached packet are instances that reflect **medical discrimination toward children with special needs.** These "horror stories" were collected after Simon's mom, conferee Sheryl Crosier, began a crusade (and self-published a book) to protect other parents from the tragedy she and her husband, Scott, experienced five years ago. 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.

The technology for saving lives in the NICU continues to improve. I have attached a new paper published this week in the prestigious Journal of the American Medical Association (JAMA) which examines the evolving way children with chromosomal disorders and their families *should* be treated. This paper promotes ending the old assumptions that diagnoses of Trisomy 13 and 18 are “fatal,” “untreatable,” and yield a low quality of life. The comparison is made to the way that the medical establishment has evolved/improved over the past century in their treatment of individuals with Trisomy21 (Down Syndrome).

There is a great public outcry that parental permission is *not* required for DNR placement. This bill passed 37-3 in last year’s Senate and we hope this committee supports passage again.

Kathy Ostrowski, Kansans for Life Legislative Director