

Proponent, HB 2307- SIMON'S LAW

House Federal & State Affairs Committee.

March 21, 2017

Chairman Barker, Vice-chairman Highland and committee members,

Good morning. Passage of Simon's Law is a top priority for Kansans for Life because **it will save lives and reinforce parental rights.**

The pressing problem is that medical personnel have issued Do Not Resuscitate (DNR) orders for children-- without notice or permission of parents. The heartbreaking evidence is in our packet, featuring testimony from families, researchers and physicians.

As further evidence, 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]

BACKGROUND

Simon's Law (HB 2307) was introduced in 2016 with the support of the disability community and national medical groups. (*See proponent testimony.*) The "tweaked" version that just passed the Senate, Substitute SB 85, is the result of consultations with Via Christi hospital leadership and the head ethicist for Ascension Hospitals, the largest Catholic chain in the nation.

As a concession, two sections from the 2016 (HB 2307) version were removed (1) on denial of food, water and medical treatment, and (2) the definition of terms relating to physiological futility. KFL will be in further discussion about those issues after this legislative session.

Do Not Resuscitate (DNR) orders for adults are governed under K.S.A. 65-4941. Simon's Law will institute a protective process for DNRs for minors:

- parents must be informed orally and in writing, before an order for a DNR can be placed in the medical chart of a minor;
- the delivery of that information (by whom, time /date) must be recorded in the child's chart;
- that order may then remain, or parents may refuse it orally or in writing;
- during conflict resolution, the child's life must be preserved.

As in the original, Sub SB 85 still also requires that hospitals and medical facilities disclose any written "futility" policies (about when life-sustaining care will be denied) to patients and prospective patients (of any age) who request it. Simon's Law does not require the creation of such policies.

The need for parental permission for DNRs **extends to any child** who faces life-threatening accidents or disease. Today, this committee is hearing from the Crosier family (with Kansas ties) and the Topeka, Kansas, Spurlock family, both whose children received DNRs due to their

children's medically fragile medical status. Our packet reveals:

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 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 that **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 hospital Neonatal Intensive Care Unit (NICU) continues to improve. A new paper published last month in the prestigious Journal of the American Medical Association (JAMA) examines the 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 authors note the way the medical establishment has evolved/improved over the past century in their treatment of individuals with Trisomy21 (Down Syndrome).

The importance of expert consultation for parents facing dire medical decisions is duly acknowledged. But Simon's Law upholds **respect for parental rights and the universal right to life**. We urge this committee to **amend HB 2307 to Sub SB 85** and pass out favorably. Thank you, Kathy Ostrowski, Kansans for Life Legislative Director