

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

MEDICAL GROUP Proponents, Simon's Law-
House Federal & State Affairs Committee

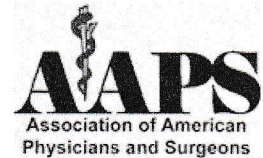
HB 2307

March 21, 2017

The American College of Pediatricians informs that, "Once inconceivable, the practice of hospital staff placing a do not resuscitate (DNR) order on a child's chart without the informed consent of the child's parents or legal guardian is on the rise. Simon's Law is designed to prevent this practice; it will guarantee parents' right to participate in the healthcare decisions of their children [in an era] increasingly predicated upon the ill-defined and subjective concept of 'quality of life' with one or more disabilities considered intolerable." Read entire ACP testimony [here](#).



The Association of American Physicians & Surgeons "holds that human life is sacred, including the life of severely disabled persons... A DNR order all too often results in withdrawal of care that would otherwise be given, even when no cardiopulmonary resuscitation is required. Care judged by some to be 'futile' is often life-saving, even if it does not restore full function. [When] there is a time when medical intervention provides no benefit, it is unethical and should be unlawful for a medical facility to determine that point unilaterally." Read the entire AAPS testimony [here](#).



The National Association of Pro-life Nurses asserts that parents have "a right to full disclosure and participation in the healthcare decisions of their disabled or severely ill children. Read entire NAPN testimony [here](#).



"**The Kansas City (Kansas/Missouri) Guild of the Catholic Medical Association** believes "Simon's Law recognizes the sacredness of life and the primary role parents have in caring for a child. ...Medical facilities or practitioners cannot and should not determine that a patient's life is no longer deserving of medical care. DNA orders can be too broadly interpreted and used to hasten death. Simon's Law embodies the most fundamental principles of medical ethics." Read entire CMA testimony [here](#).



Kansans for Life

Re: FUTILITY POLICIES & "ETHICS" PANELS

Futile Care: Futile care is a form of ad hoc health-care rationing. Doctors and hospital bioethics committees are **empowered to refuse to provide wanted life-sustaining treatment, based on their perception of the patient's quality of life and/or cost-of-care** considerations—a true "death panel." The bioethics movement has been quietly pushing futile care for years, with mixed success, mostly via internal hospital administrative policies....look for increased legislative efforts to grant bioethics committees the legal **right to make the ultimate decision** about whether to provide life-sustaining medical treatment.

-Wesley J. Smith <https://www.firstthings.com/web-exclusives/2017/01/bioethics-in-2017>

Over the past decade many articles in legal, ethical and medical journals have argued for a new concept in health care and in treatment decisions called "medical futility." ...Part of the problem lies in the lack of agreement about what "medical futility" actually means. In terms used by its proponents, **medical futility means that a physician can refuse to provide a patient with treatment that he or she does not believe to be useful** for the patient. After years of promoting the patient's autonomy in health-care decisions, now, with medical futility, some ethicists argue for a limitation on the patient's decision-making power.

Of course physicians should not be required to provide medical interventions that offer no medical benefit. But that is not what the current theory of medical futility is about or what the authors mean by irrational. According to the **principles of medical futility, proponents are seeking to terminate treatment precisely because it actually does sustain life.** To put it in the words of anti-euthanasia task force lawyer Wesley Smith, "It isn't the treatment that is deemed futile but, in effect, the patient.

"Treatments withheld under this policy might include antibiotics to treat infection, medicines for fever reduction, tube feeding and hydration, kidney dialysis or ventilator support."

-St. Louis Review <http://stlouisreview.com/article/2001-12-06/futility-policies-part-culture-death>

Who should have the right to decide whether you receive life-sustaining medical treatment during a critical or terminal illness?

Most would say with great confidence, "Me. Or, if I am unable to decide, then my family." That should be true. Indeed, it used to be true.

But in a growing number of hospitals, your **right-to-decide is being taken away from you (or your family) by bioethicists and members of the medical intelligentsia** who believe that their values and priorities should count more than yours when determining whether you shall receive wanted medical treatment.

To put it bluntly, even if you want to live, even if you want medical treatment to enable you to fight for your life, you may be told that the **hospital reserves the right to refuse service.**

(continued)

Welcome to the world of "futile-care theory," one of the hottest and **most-dangerous** topics in contemporary bioethics.

While you may never have heard of it, stories about the **spread of futile-care theory** are rife throughout medical and bioethics literature, reported and argued about in such influential publications as The Journal of the American Medical Association, The New England Journal of Medicine, and The Hastings Center Report.

Unfortunately, few people read these highbrow publications. Worse, despite being a bombshell story, this growing threat has mostly been ignored by the popular media. This better change fast. As you read these words, quietly, slowly, inexorably, mostly behind the closed doors of hospital ethics committees, **"futile care" or "inappropriate care" protocols are being put into place in hospitals throughout the country.**

The first time most patients and their families become aware that doctors are being given the right to say "no" to wanted medical treatment (other than comfort care) is **during a medical crisis when they are at their most defenseless** and vulnerable. Hospitals in Des Moines, Iowa, appear to be the latest institutions to **stealthily adopt** futile-care policies. As reported by the January 2, 2003, Cedar Falls Courier, some area hospitals now have rules in place that **permit "medical staff to withdraw treatment over a family's objection."** True, when there is a dispute, families and patients have a right to a hearing in front of a **hospital ethics committee. But that isn't much solace.** Such committees could easily become more stacked decks than dispassionate decision makers, mostly comprised of well-meaning people who either are part of the institutional culture or who have been trained to believe that futile-care theory is the right thing to do. Wesley J. Smith <http://www.nationalreview.com/article/205410/doc-knows-best-wesley-j-smith>

[S]ome hospitals are... promulgating "futile-care" protocols that grant **doctors the right to say no to wanted life-extending medical treatment to patients whose lives they consider lacking in sufficient quality** to justify the cost of care.

It wasn't much more than 20 years ago that withdrawing tube-supplied food and water from a patient due to cognitive disability was virtually unthinkable in clinical medicine. Indeed, it **would have been a crime** in many jurisdictions.

However, by the early 1990s, in the wake of the Nancy Cruzan case, virtually all states permitted families to decide to withdraw tube-supplied nutrition and hydration as a matter of the "right to die." Today, throughout the country, conscious and unconscious cognitively **disabled people are intentionally dehydrated to death** almost as a matter of medical routine when families consent.

Some futile-care policies don't even identify the maladies for which treatment will be refused but leave it to doctors to decide on a case-by-case basis. But what happens if the patients or families object to the denial of care?

Many futile-care policies establish review procedures under which **hospital ethics committees,** originally established as mediating bodies to help families and physicians negotiate the proper approaches in difficult cases, **are given adjudicatory authority to determine whether patients receive treatment or have it terminated.**

National Right to Life News Today <https://www.nrlc.org/archive/news/2000/NRL12/wes.html>