

'Simon's Law' considers parents' role in health-care decisions

Jennifer Brinker | jbrinker@archstl.org, JANUARY 28, 2015



Simon Crosier was born with Trisomy 18, a genetic disorder that includes an extra chromosome 18.

A bill proposed in the Missouri House would prohibit health care facilities and others from withholding life-sustaining procedures from a minor patient without the written consent of a parent or legal guardian.

Sponsored by Rep. Bill Kidd, R-Kansas City, [HB 113](#) also would require health care facilities, nursing homes and physicians to disclose in writing any policies that relate to a patient's care, including life-sustaining or non-beneficial treatments.

The bill is nicknamed "Simon's Law" after [Simon Crosier](#), who was born in 2010 with Trisomy 18, a genetic disorder that includes an extra chromosome 18. Simon lived three months.

His mother, Sheryl Crosier, a member of Annunciation Parish in Webster Groves, wrote a book in 2012, called "I am Not a Syndrome -- My Name is Simon." In the early stages of her research, Crosier was going through Simon's medical records and discovered that doctors had placed a "do not resuscitate" order in her son's records without her knowledge, she said. He also was ordered to receive nutrition as a comfort measure only. Turns out, the hospital had in place a futility policy, which allows physicians to withdraw medical treatments deemed to be "futile."

"They took the road they wanted to go," said Sheryl Crosier. "They started taking away, stripping him of everything. They would say, things like 'not for Simon,' or 'incompatible with life.' It was very dehumanizing."

In 2013, the Crosiers met with a film producer who was working on a documentary on families with children who have special needs. The Crosiers discovered they were not alone. Several others families shared stories of not being

informed whether the hospital had a futility policy and what rights they had as parents in making decisions for their children.

Last fall, Crosier shared her story at a Missouri Right to Life event in Kansas City. There, she met Kidd, who was moved by her story.

"This should not even occur," said Kidd. "Removing life-sustaining treatment (without permission) is punishable by law, but it's being done and off the books, from my understanding. Morally and ethically they should inform the parents and that's not always happening. This is about parental rights. If treatment is going to be withheld, then the parents have to have it in writing."

The bill has been assigned to the Health and Mental Health Policy Committee; a hearing has not yet been scheduled.

Dr. Peter Morrow, president of the Catholic Medical Association, noted that not all health care facilities have futility policies in place, and there isn't a uniform application among those that do. A [2007 position paper](#) by the CMA noted that the concept of medical "futility" emerged in the 1990s, when medical and bioethics began promoting the idea connected to cases where patients or family members insisted on treatment over the objections of physicians and/or health care institutions.

The CMA, which does not endorse the concept of "medical futility," included in its position paper a Catholic framework for addressing claims by families of inappropriate treatment. While not all health care facilities have futility policies, most have ethics committees, said Morrow, which also address issues related to patient care.

Crosier urges people to contact legislators in support of the bill. "If people feel strongly about their parental rights ... it's very important to have this law," she said. "If we had Simon's Law, this would not have happened, because we would have been the ones making the decisions -- even if it would have been to put the DNR, we would have been the ones making the decision."

To read more about Simon Crosier's life, visit www.simonismyname.com.

What is medical futility?

- Futility policies have been adopted in several cities and states that rely on procedural grounds rather than widely accepted definitions of "futility." These policies permit unilateral decisions by physicians/hospitals to withdraw medical treatment deemed to be "futile."
- Beginning in the 1990s, the concept of medical "futility" was advanced in the medical and bioethics literature in connection with cases in which patients or family members insisted on treatment over the objections of physicians and/or health care institutions.
- Over the next ten years, a variety of definitions and categories (e.g., quantitative and qualitative) of "futility" were proposed; none achieved widespread support. Rather, there was general agreement that consensus on definitions and on individual cases was unlikely, if not impossible.
- There has been widespread agreement that the development and implementation of futility policies is fraught with dangers — that conflicts between patients/families and physicians/hospitals are best avoided in the first place or addressed in a non-confrontational manner once they arise.

From "Guidelines on Resolving Conflicts About Treatment Deemed 'Futile,'" Catholic Medical Association, 2007.