

Proponent, Simon's Law-SB 85

Feb. 16, 2017

Chairman LaTurner & members of the Senate Federal & State Affairs Committee,

My name is Amy Reynolds. I am a Kansas mother who gave birth nearly 15 years ago to a child who had anencephaly. I believe my written testimony is relevant to passing Simon's Law.

My husband and I had tried to get pregnant for four years when we finally conceived our daughter, Gracie. At 10 weeks gestation, we found out the terrible news that she had a fatal condition called anencephaly. Her brain would not ever develop and she would not be able to survive for long outside of the womb.

Some thought it would be easier for me to terminate my pregnancy, but nothing could be further from the truth. We prayed to be parents, and now we were. We wanted to do everything we could for our daughter while we had her. She was stillborn on March 4 of 2002. I was able to feel her kick, hold her, name her, and give her a proper funeral. None of which I would be able to do had I terminated.

What I wanted from the medical community was to treat my daughter and I in the same way they would if I was expecting a healthy baby. I wanted all the prenatal care I needed to be able to deliver her alive and to keep her with us as long as we could. Luckily, I had a good OB/GYN who respected my wishes. She wasn't born alive. We knew that was one of the possible outcomes. I am at peace that we did all we could to be good parents to her while we had her.

Had she been born alive, I would expect all reasonable care to be given to her. Given her fatal prognosis, I probably would have signed a DNR not to resuscitate. I would have expected, though, that this would be discussed with my husband and I and that we would be the ones to make that decision.

I believe in respecting and preserving life from conception to natural death. I understand that she could not live long with her condition but I still would not do anything to hasten her death. If my child were to be diagnosed later in life with terminal cancer, I would not want them to euthanize her or do anything to hasten her death. I would want her to be treated with everything to make her remaining life as comfortable as possible, as would any parent.

My cousin had a child with Trisomy 18. She lived 6 months. They and their medical community did all they could to make her life as comfortable as possible for as long as

possible. I assumed this is the common procedure among all parents and medical providers faced with this situation. I was shocked to learn that it is not.

I cannot believe that anyone in the medical community would put a DNR order in a child's chart or deny any basic care (like food and water) to a child just because they determined that that person's life was not worth saving. That is a personal decision to be made by the parents. I believe that the decision needs to be an informed decision made with the parents and doctors together so that reality and all possible outcomes can be discussed.

By no means does the medical community get to make that decision on their own.

It was devastating to lose our daughter. No matter what condition she had, I would hate to learn that my daughter's life was cut even shorter than it was meant to be with no knowledge or consent from me.

Part of being a good parent is to provide for and speak for them when they cannot. Under no circumstances does a child or anyone else need to be starved to hasten their death. I would hope that a common sense law like Simon's law would be passed with ease. What I'm most surprised by is the necessity of such a law.

Our daughter was our daughter no matter her diagnoses. She was special and very loved and deeply missed. To us, and to any other parent, they are a part of the family and **not just some unfortunate case to be discarded**. It is the medical practitioner's duty and oath to take care of people **not to decide on their own who is worthy to live and who is not**. Thank you for your time and I look forward to seeing Simon's law passed.

Sincerely,
Amy Reynolds
21708 W. 57th Terr.
Shawnee, Kansas 66218
email: ajrwmk@everestkc.net