

**Testimony on Senate Bill 85
Federal and State Committee
February 16, 2017
Kathy Davis, PhD
Chair, Pediatrics Ethics and Palliative Care Committee**

Chairman LaTurner and Members of the Committee,

My name is Kathy Davis, PhD and I am the Chair of the Pediatrics Ethics Committee at The University of Kansas Medical Center. I am reaching out to you to share my concerns regarding SB 85 – Simon’s Law. These concerns are my own and based on 35 years in the field of pediatrics and my experience as the Director of Palliative Care and Chair of Pediatrics Ethics, which is comprised of hospital employees, faculty in the Department of Pediatrics and community members, who are strong voices for the lay perspective of what is in the best interest of a child. I am not contacting you on behalf of The University of Kansas Health System, The University of Kansas Medical School, or other entities of KU.

There is a reference to health care being deemed “futile” in the bill which is cause for concern. The term “futile” is no longer typically used in ethical decision making and suggests that a treatment is no longer effective or achieving the desired effect. When physicians recognize that a treatment is ineffective, they have a duty to communicate that the treatment cannot benefit the patient. Because it is often used imprecisely, the term “futile” can cause confusion and exacerbate conflict in disagreements about end-of-life care. About 5 years ago, I was part of a national ethics committee and we attempted, for about a year, to define “futile” and “futility”. We concluded that it was not possible due to the various ways the term is defined by individuals and the ambiguity that results. It is more helpful for patients, families, and physicians to discuss the **benefits and burdens of medical procedures; risk or benefit of treatment; or whether a certain treatment is helpful or harmful rather than talking about the vague, ambiguous term “futile”.**

In addition, it is important to note Do Not Resuscitate (DNR) has been replaced by Do Not Attempt Resuscitation (DNAR). A DNAR is a more accurate term, enabling parents to know that a Code Blue is an *attempt* to resuscitate the child and help them to understand that the child may die despite the best efforts of resuscitation.

Currently, it is deemed unacceptable practice for a healthcare facility, nursing home, physician, nurse or other medical staff to withhold or restrict life-sustaining procedures, food, medications, or nutrition from any patient prior to in depth discussion(s) with the patient or patient proxy/parent. Current practice is to institute a DNAR order only after extensive education, dialogue and consultation with the infant’s or child’s parents. This is typically a series of conversations over days, weeks or months. These conversations include not only the physician but also nurses, residents, social worker, medical students, nutritionist, pharmacist and sometimes the ethicist. With electronic medical records (EMRs), every professional working with an infant or child has ready access to all orders in the child’s chart and a ‘secret’ DNAR would not survive that oversight. The practice of cardiopulmonary resuscitation (CPR) is not done by a single physician in isolation. It is done by a large team of people. When a hospital patient stops breathing or has no heart beat, a “Code Blue” is called. When a Code Blue is called in a hospital,

healthcare professionals come running from a variety of units. There are several doctors, nurses, anesthesiologists, respiratory therapists, resident physicians and medical students who respond to the call. Several people are working, aggressively, on one tiny person.

The following are a few reasons why a DNAR would not be implemented without parental consent:

- First and foremost, each precious infant or child who is cared for is valued. I watch physicians, every day, work just as hard to save the life of a child with special needs as they do a typically developing child. I am involved in ethics and palliative care on the national level, and this mindset – valuing all children – is a standard.
- Medical care teams conduct a “goals of care” meeting with patients and/or parents when life-limiting conditions exist. This meeting is to ensure patient and family wishes are discussed with all professionals on the care team. The entire care team (all physicians, resident doctors, medical students, social workers, nurses, etc.) has knowledge of a DNAR order because all must know in case the issue arises when they are in charge. A DNAR would never be accepted by other health care professionals who attend family meetings when a child has a potentially life-limiting diagnosis or enter and read the child’s chart.
- Physicians have a high and ever growing degree of respect for human life, whether the child has a disability, life-limiting illness or is without disability or illness.
- Physicians have a high and ever growing respect for parents’ right to make decisions for their own baby/child unless there is concern for the best interest of the child.
- Pediatric ethics committees are consulted when there are any questions, concerns or differences of opinion between physicians and parents. This practice provides the oversight that SB 85 suggests is needed. That being said, physicians are not in the practice of “telling” parents or patients what they should or should not do. Rather, they inform parents of what is occurring in their child’s health situation and provide information about various options. In the case of a physician and the parent having a different belief, the parent choice prevails. Pediatrics, as a field, holds very strongly to the concept that parents are the best decision makers for their child because they best know the child’s/family’s beliefs, culture, faith, etc. In addition to believing that parents are in the best position to be their child’s surrogate, it is also widely held in the field of pediatrics that parents have the *right* to be the child’s decision maker. Thus, “differences of opinion” do not actually occur. An exceptions may occur if the physician believes the baby/child is experiencing suffering that cannot be controlled with medications or treatments. In that case, the physician would likely stress that point and provide a recommendation. But not a ruling.
- After a DNAR decision is made, parents are informed that they may make any changes to the original decision at any time. When changes are made, they are noted in the EMR immediately.
- Parents and physicians may have several meetings that lead up to a decision regarding the care the baby or child will receive going forward. These discussions are usually exquisitely both painful and beautiful, as all work toward what is in the **child’s best interest**. A litigious process creates an adversarial tone where someone is deemed “right” and someone else is determined to be “wrong”. This **cannot be in the best interest of a dear baby or child** and adds undue burden to already emotionally overwhelmed parents.

I am involved in a majority of conversations between physicians and parents regarding decision making of a serious nature for an infant or child. During my many years at KUMC, I have never been

concerned about a DNAR being instituted without full parental agreement. If two parents disagree about whether or not to provide a DNAR for an infant/child, physicians defer to the parent who is in favor of life-sustaining procedures since the other decision leaves no alternatives to be tried at a later time. I watch physicians who work very hard to ensure that they and the parents of the child are collaborating effectively to meet the best interest and needs of the child. These physicians would never opt to make a decision to institute a DNAR or withhold life-sustaining treatment without the agreement of the parent. And, with the existence of the electronic medical record where all decisions must be entered and visible to the entire healthcare team, there is no feasible way that a unilateral DNAR could be initiated. There are too many eyes on the infant/child's chart and too many individuals who are aware of parental choice to make a unilateral DNAR possible. It is like saying that one legislator could enact a bill and make it law without the knowledge or input of any other legislator.

In pediatrics, we fully understand and appreciate that "quality of life" is defined differently by every family. Therefore, it is our responsibility to support and preserve the quality of life of each individual fetus, infant, or child as set forth by the parents. Only parents fully know and understand their family values, culture and religious beliefs that affect such heart breaking decisions. The issue of "quality of life" of a child with special needs is not considered to be any less precious by the healthcare team. We are committed to clear and continuous communication with families to ensure that they have an understanding of the information that is known by the healthcare team so they can make informed decisions that are in concert with their family beliefs, and that the healthcare team has an understanding of what is important to the family, so we may extend understanding and empathy. Very simply, the parents' choices drive the plan of care.

The concept that medical care teams would institute a DNAR or withhold life-sustaining treatments without parent agreement is an irrational concept, and one that is insulting to the professionals who work tirelessly to treat, care for (and about), and protect their young patients. They want nothing more than the patient's survival. The focus for physicians and staff is the best interest of the child. When physicians and parents are working together it creates the best team to determine a child's true best interest and initiate a plan of care that will support the child and the family. The physician's expertise and knowledge combined with parents' love and commitment to their child enables parents to make the decision which is best for their child.

Should you have questions or seek further information, I can be reached at kathygdavis2@gmail.com or (913) 206-3521. Thank you for your time and consideration of my concerns.

Sincerely,
Kathy Davis, PhD
Chair, Pediatric Ethics and Palliative Care
University of Kansas Medical Center