

**TESTIMONY OF SUSAN KLEIN**  
**Legislative Liaison, Missouri Right to Life**  
**In Opposition to**  
**HB 785, the “Adult Health Care Consent Act”**  
**April 15, 2015**

I urge you not to send H.B. 785, the Adult Health Care Consent Act, to the floor.

A wide group of organizations of differing perspectives have been negotiating for months to produce agreed legislation that addresses the subject matter of H.B. 785 in the form of the Designated Health Care Decision-maker Act. It is that painstakingly constructed bill, which is acceptable to numerous stakeholders, that instead should be enacted by the Missouri legislature in this session.

In addition, there are significant problems from the pro-life viewpoint with H.B. 785.

First and foremost, unlike the Designated Health Care Decision-maker Act, H.B. 785 fails adequately to protect patients from involuntary denial of life-saving health care by health care providers based on the providers claim that the patient’s “quality of life” is too poor. Section 404.902.2 limits surrogates decisions to direct life-preserving treatment to patients to those within “prevailing medical standards.” The sad reality is that numerous bioethical and medical journal articles, as well as statements by prestigious medical organizations could be cited as establishing a “prevailing medical standard” that health care providers should not provide life-preserving treatment to patients whose quality of life, because of age, disability, or another factor, they believe not to be worth preserving, regardless of the views of the patient or patient’s surrogate<sup>1</sup>. H.B. 785 neither includes language protecting against discriminatory denial of treatment based on disability nor provides for provision of directed life-preserving treatment pending transfer to a willing health care provider.

While the bill does provide for the opportunity to bring treatment disputes to court through the guardianship-appointment, it fails to include the crucially important requirement that life-preserving treatment be provided until final judicial resolution of such disputes.

Section 404.906.2 authorizes physicians unilaterally to deny treatment against the directions of surrogates, upon the physician’s claim that this is what the patient told the physician she or he wanted– thus making the doctor simultaneously witness, judge, and jury in the first instance. Anyone who claims to know what the patient would have wanted, whether or not that person has an “M.D.” after his or her name, should be free to share that information with the decision-maker(s), but if someone wants to claim that the designated decision-maker’s direction disregarded based upon evidence that person claims to be able to provide concerning the patient’s wishes, the appropriate forum, is a probate court proceeding. In that setting, testimony can be presented and challenged, tested by cross-examination and argument. Due process can be accorded before anyone’s participation or views are excluded. It is true that the bill allows a court proceeding to override the health care provider’s unilateral decision to deny treatment, but by the time such a proceeding can be held it could be too late if immediately necessary life-saving treatment is withheld.

Section 404.902(4) provides that if a health care professional “has reasonable cause to make a report of abuse or neglect of the patient . . . the individual to be reported shall not be given authority [to make health care decisions on behalf of the patient] regardless of the purpose of the treatment.” This seemingly praiseworthy provision unfortunately establishes an additional means by which physicians who strongly believe that a patient should die because of a supposed poor quality of life can disregard a surrogate’s directions to provide life-preserving treatment. Certainly

there is reason to question the validity of someone who has abused or neglected the patient making medical decisions for that patient. However, note that the reported individual is completely excluded from being a decisionmaker *simply because of the doctor's or other health care provider's view* that there is reasonable cause to make a report, not because of any judicial or even administrative finding that the report is warranted.

Why is this potentially dangerous? Sadly, there is an increasingly pervasive view among many in the medical profession – not all – that preserving the life of someone whose quality of life they deem to be too poor is itself a form of abuse. The title of one law review article typifies this position: “When Vitalism is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment”<sup>2</sup>. A physician who agreed with the perspective of that article’s author could unilaterally disqualify a pro-life surrogate because the doctor considered a decision for life-preserving treatment to constitute abuse of the patient – very erroneously, we would argue, but sincerely under his or her quality of life ethic.

Finally, throughout the bill, there are numerous instances in which decisions by health care professionals are held only to a subjective, rather than an objective malpractice-type standard of reasonable medical judgment.

I have given you an illustrative rather than an exhaustive list of the problems with H.B. 785.

Rather than advancing H.B. 785, even with corrective amendments, Missouri Right to Life urges that the Designated Healthcare Decision-maker Act, the product of careful and lengthy negotiations among the principal interested organizations, be the vehicle to address this area of law.

<sup>1</sup>*“At its core, the dispute in futility cases is about quality of life: Who decides what it is and when, if ever, it justifies the administration or foregoing of life-sustaining treatment.” Alan Meisel & Kathy Cerminara, The Right to Die The Law of End of Life Decisionmaking (3rd ed. 2014) §13.03. E. Haavi Morreim states it “revolves around fundamentally irresolvable moral conflicts concerning our most deeply held beliefs about the value of life, especially profoundly diminished life.” Catherine A. Marco, Gregory L. Larkin, John C. Moskop and Arthur R. Derse, state (in “Determination of Futility in Emergency Medicine,” Annals of Emergency Medicine June 2000 pp. 604-612) that “there may be an ethical obligation to withhold ... treatment, particularly if it entails significant risk or cost.” W. Daniel Doty maintains, “The greatest injustice routinely endured in the current system is maintaining patients...with invasive treatment modalities simply because they live in a technological era.... Expending resources on imminently dying patients is unethical because it supports selfish individualism at the expense of society.” “Medical Futility,” Clinical Cardiology, February 2000 Supplement II-6 - II-16 Leslie Whetstine and David Crippen claim “If the proposed intervention is costly, the ethical principle of justice becomes an important consideration. Justice requires physicians to make wise use of health care resources.... The treating physician’s ethical obligations . . . logically limit the patient’s autonomous choices to those options the physician can ethically offer.” “Desire vs. Need in the Medical Marketplace,” Cost & Quality, September 1999, 31-33.*

<sup>2</sup>79 Ind. L.J. 1 (2004).