TESTIMONY OF SUSAN KLEIN
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In Support of H.B. 2502, the "Designated Health Care Decision-maker Act"
Before the Civil and Criminal Proceedings Committee
March 2, 2016

On behalf of Missouri Right to Life I urge you to support H.B. 2502, the Designated Health Care Decision-maker Act, and send it to the floor after correcting some mistaken cross-references.

A wide group of organizations of differing perspectives has been negotiating for years to produce a painstakingly constructed bill, which is acceptable to numerous stakeholders. On balance, Missouri Right to Life is convinced that this bill contains solid protections to protect the right to receive life-saving medical treatment, food and fluids, and in important respects is significantly more protective than current Missouri law.

Let me highlight two aspects of the bill that make it a significant pro-life advance.

First is a particularly important improvement over current law: the Designated Health Care Decision-maker Act contains anti-discrimination language that effectively protects 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.

The sad reality is that numerous bioethical and medical journal articles, as well as statements by prestigious medical organizations, maintain that health care providers should not provide life-preserving treatment to patients whose quality of life, because of age, disability, or terminal illness, they believe not to be worth preserving, overriding the clear directions of the patient or the patient's health care decision-maker. They seek to impose their value judgment that certain lives are not worth living, contrary to the view of the patient whose life it is. Section 404.1108.4 includes language to prevent denial of treatment directed by the patient or health care decision-maker if that denial is based on the patient's age, disability, or terminal illness. Even when treatment necessary to preserve life is involuntarily denied for other reasons, the section requires provision of such treatment, when directed by the patient or health care decision-maker, while awaiting transfer to a willing health care provider.

Second, the bill provides a positive way of resolving disagreements among potential health care decision-makers at a time when the patient is unable to speak for himself or herself. While the bill assigns an order of priority among eight (8) classes of family members and others who are potential decision-makers, it allows anyone in those classes who has evidence that the prioritized decision-maker is not acting according to the patient's wishes or best interests to seek a resolution through a judicial proceeding that provides for due process. Of critical importance, section 404.1104.9 preserves the patient's life while the matter is being litigated.

Finally, while anyone reported for abuse or neglect is not given priority among the potential decision-makers, section 404.1104.4(1) prevents misuse of the reporting system to claiming, as some have, that supporting or directing the provision of health care to preserve the patient's life itself constitutes abuse or neglect of the patient. The inclusion of this protective provision is critical to Missouri Right to Life's support for the bill.

If H.B. 2502 is enacted, Missouri will be among the foremost states in protecting its residents against involuntary euthanasia. I urge your support for it.

“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.