

**Testimony in Support of HB2031 – The Palliative Care and Quality of Life Advisory Council
Committee on Healthy and Human Services
Tuesday, February 07, 2017
1:30 PM Room 546-S, Capitol Building, Topeka, KS**

John G. Carney (jcarney@practicalbioethics.org)
President and CEO
Center for Practical Bioethics
Kansas City

Chairman Hawkins and Members of the Committee:

Thank you for the opportunity to speak in favor of House Bill 2031 to create the palliative care and quality of life interdisciplinary advisory council. This council will serve to benefit the citizens of Kansas in myriad ways by helping individual healthcare consumers to understand better the options they have in accessing appropriate services to match their values and preferences regardless of the diagnosis, treatment options or conditions with which they live, so they may live longer and more productive lives.

This measure can also assist healthcare professionals by further promoting and demonstrating the benefits of team based care and constant attention being given to patient's involvement in achieving better outcomes.

Palliative care is still a poorly understood service by the general population, often overly identified with hospice care, with which it shares some tenets but is not identical.

In an effort to provide those distinctions we respectfully **request that the Committee consider additional clarification under Sec(b)(1)(C)** that identifies other health conditions beyond hospice that require intense palliative care involvement such as "advanced illness, and chronic disease and conditions that require significant attention to symptom control to improve patient function and health outcomes."

The bill provides ample opportunities for the interdisciplinary nature of palliative care to be reflected in the appointments to the council. However, given the nature of the focus on patient involvement in shared decision-making and active participation by the patient in setting goals of care - a hallmark of palliative care— the **advisory council should have at least one member designated as representing the patient/family perspective.** There are many qualified individuals and patient advocates who could assume that role. To populate the council with only healthcare professionals would give the impression of once again diminishing the critical aspect of patient centeredness that palliative care works so hard to protect.

One caution we would ask the Committee to consider is the over-dependence in statutory language under Section 2(b)(1) by identifying the "website" as the mechanism for distribution of information. We would recommend using **such language as "utilizing electronic means"** as a substitute for manner and methods we use to share palliative care resources, education, and services.

Thank you for the opportunity to share this testimony with you and we commend the committee for consideration of this important legislation.

Respectfully Submitted
John G. Carney
President and CEO, Center for Practical Bioethics