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Neutral Testimony on SB250
House Committee on Health and Human Services
Kansas State Board of Healing Arts
March 7, 2025

Chair Carpenter and Honorable Committee Members,

Thank you for the opportunity to provide this neutral testimony concerning SB250. My name is Susan Gile, and I am the Executive Director for the Kansas State Board of Healing Arts ("KSBHA" or "Board"). The Board is the executive body tasked with licensing and regulating 16 different healthcare professions in Kansas. *See* K.S.A. 65-2801 *et seq*. The Board is composed of 15 members, 12 of whom are licensed healthcare professionals from various professions, including eight licensed physicians, three chiropractors, one podiatrist, and three public members. **The statutory mission of the Board is patient protection**. *See* K.S.A. 65-2801.

I'd like to begin by stating that SB250, also known as the Right to Try Act, is a very well-intentioned bill. As mentioned during the Senate hearing, any compassionate person would be fully supportive of this bill.

With that said, the Board does have some concerns with some of the bill's provisions. As mentioned above, the Board's fundamental mission is patient protection. The patients who would qualify under this bill are some of the most vulnerable served by licensees regulated by the Board. They are either terminally ill or living with a debilitating condition. Patients in these circumstances are undoubtedly prone to putting faith in untested treatments for their conditions. As another conferee mentioned, these patients are looking for hope. This provides a prime opportunity for bad actors to prey on their vulnerability.

While we all would like to believe that our world is full of only scrupulous people who would not dream of taking advantage of others misfortune, we sadly know this is untrue. While confidentiality statutes prevent me from providing details, I can tell you that we currently have a number of cases where providers have knowingly and purposely preyed on those with chronic pain (often the elderly). These providers promised these vulnerable patients remarkable results for treatments that are not scientifically proven nor accepted. Some of these patients have spent tens of thousands of dollars on treatments that have at best, provided no benefit. At worst, these treatments resulted in negative outcomes including infections, severe and chronic pain, loss of limbs, and more.

- Our first concern with SB250 as written is Section 1(a)(5), which outlines the requirements for written informed consent. As defined in the bill,

> "(5) "Written, informed consent" means a written document that is signed by the patient, a parent if the patient is a minor, the legal guardian of authorized representative as

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defined in K.S.A. 65-6836, and amendments thereto, and attested to by the patient's physician **and a witness** that includes all of the following:"

We believe that it is important to define or clarify that the "witness" *must* be someone unaffiliated with the Physician's office. It must be clear that the patient is signing freely, and that they have a clear understanding of what they are signing.

- To that end, the Board's second concern with this legislation is Section 1 paragraph (B). This is included in the requirements for written, informed consent, and requires patients to provide:

> "(B) An attestation that the patient concurs with such patient's physician and that all currently approved and conventionally recognized treatments are unlikely to prolong the patient's life;"

This paragraph would require the eligible patient to make an assessment that is far beyond their knowledge and skill. The average patient simply would not have the necessary knowledge to attest to this.

- Our final issue with SB250's language concerns payment. This is addressed in two sections of the bill:

1. Sec. 1(a)(5)(G) (Pg 2, lines 28-32) "a statement that the patient understands that such patient is liable for all expenses related to the use of the individualized investigational drug, and that this liability extends to the patient's estate, unless a contract between the patient and the manufacturer of the drug, biological product or device states otherwise."

2. Sec. 1(e) (Pg 3, lines 23-26) "If a patient dies while being treated by an individualized investigational drug, biological product or device, the patient's heirs shall not be liable for any outstanding debt related to the treatment or lack of insurance due to the treatment."

We believe that it must be made *abundantly* clear to potential recipients of these treatments that, although their surviving family may not be held liable for remaining payments, the estate may be attached. Having this clarity may impact some patient's decisions.

As you may notice, the common thread throughout my testimony is the need to provide patients with the most comprehensive and accurate information available, to ensure that their ultimate decision is made free of duress, and that patients have a clear understanding of the potential outcomes and implications of this treatment. I appreciate the committee's time and consideration of these suggestions. The Board's goal is simply to protect patients from potential unscrupulous actors. I am available for questions at the appropriate time.

Sincerely,

Susan Gile

Susan Gile
Executive Director

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