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March 5, 2025

RE: Kansas SB 250

I appreciate the opportunity to provide written remarks in support of SB 250, the Right to Try for Individualized Treatments. This legislation is vital for preserving the right to try to save one's own life without being required to plead with the federal government for permission to do so.

The Right to Try for Individualized Treatments, as before you in SB 250, applies to novel, bespoke treatment for rare diseases. These treatments are custom-made and based on one's own genetic profile. This legislation is made necessary because the FDA's regulatory scheme has not kept pace with advances in medicine. The current federal drug approval process simply did not contemplate, and is not designed to effectively or efficiently consider, treatments based on individual genetic profiles.

Kansas has an important opportunity to lead in resolving this issue for patients with rare diseases, and thereby potentially save lives, by enacting the Right to Try for Individualized Treatments. The original Right to Try gave patients the right to seek treatments that had passed the FDA's safety trials but were still undergoing trials to determine their efficacy before receiving final approval. The original Right to Try Act passed in 41 states. Ultimately in 2018, Congress passed, and President Trump signed into law the federal Right to Try Act.

The original Right to Try has made a dramatic impact in patients' lives. As an example, consider glioblastoma, an aggressive form of brain cancer. Historically, glioblastoma has a median length of survival of 8 months, and a 5-year survival rate of only 7 percent. Often, patients are left with no promising treatment options. However, because of the original Right to Try, some patients who were previously ineligible for a clinical trial can now access an immunotherapy treatment. Instead of being sent home to put their affairs in order, these Right to Try patients have a median survival of nearly 22 months.

Because of continued medical advancements in genetic medicine, Right to Try needs to be updated. Individualized treatments, based on one's specific DNA profile, are not covered under by the federal Right to Try law. Thus, Right to Try for Individualized Treatments is necessary.

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Right to Try for Individualized Treatment, as encapsulated in SB 250, would create a new, safe, and physician-directed pathway for patients with ultrarare, life-threatening or debilitating diseases for whom there are no other treatment options available and who could potentially benefit from an individualized treatment based on their unique genetic profile.

Pioneering medical innovations now make it possible to create individualized treatments based on unique genetic information. However, the current FDA clinical trial evaluation system was designed for evaluating drugs that would be used to treat large populations. Thus unfortunately, these individualized treatments are still subject to the same clinical trial process as medications intended for thousands.

The Right to Try for Individualized Treatment Act accounts for advancements in genomic medicine and the innovations that provide the means to create a bespoke medical treatment based on one's unique DNA profile. Right to Try for Individualized Treatments is already law Arizona, Nevada, Arkansas, Louisiana, Mississippi, North Carolina and Maryland. The legislation is being considered in numerous states this legislative season.

Though individualized, bespoke treatments are being pioneered domestically and abroad, patients from the U.S. often must travel thousands of miles to receive these potentially life-saving therapies. This is unnecessary. Kansas can continue to be a leader in getting the right treatment, to the right patient, at the right time.

It is important to note that removing the federal bureaucratic process that hinders these treatment options requires no additional taxpayer investment. It can also assuredly be achieved in a manner that addresses patient safety concerns and preserves informed consent.

Kansas lawmakers have the authority, and before them the legislative vehicle in SB 250, to unleash the potential of today's medical innovations to further benefit patients.

Thank you for your time and consideration.

Respectfully,

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