February 14th, 2025
Senator Beverly Gossage
Chair, Senate Committee on Health and Welfare

Senator Gossage and Members of the Committee:

Thank you for the opportunity to share my family's story and why SB 250 is important to us and other families with children who have rare diseases. My name is Kendra Riley, and I am the mother to three children, two of which who were diagnosed with a rare genetic disorder.

Five years ago, my middle daughter Olivia was diagnosed with metachromatic leukodystrophy (MLD), a rare and aggressive genetic disorder that attacks the brain and nervous system. She was rapidly losing the ability to walk and talk, and our doctors told us that Olivia's condition would continue to worsen. Olivia was not even two years old at the time of diagnosis.

A few months later, our youngest daughter, Keira, was diagnosed with the same genetic disorder. But unlike her older sister, Keira had not yet begun to show symptoms. Catching Keira's diagnosis early gave us the opportunity to try to save her life, since there was a cutting-edge gene therapy treatment that was showing promising results in non-symptomatic MLD patients.

Unfortunately, since Olivia was already showing symptoms, this treatment could not help her, but it could potentially save Keira's life if we moved quickly. There was only one issue – this personalized gene therapy which would be tailored to Keira based on her DNA was not available in the United States due to the FDA's outdated drug approval process.

In order to get Keira this promising individualized treatment, we packed up our family and relocated to Milan, Italy for nearly half of a year – during the global pandemic no less. In a matter of one month, we were able to raise the hundreds of thousands of dollars needed to get our baby girl to Italy in time to receive treatment before it was too late. Other families are not so lucky. This is why SB 250 is so important to families like ours. As genetic testing allows doctors to catch rare diseases earlier and personalized medicine advances, I fear more parents will face situations like ours.

Keira's individualized treatment was a life-saving success, and she's now a vibrant child who loves gymnastics, swimming and singing like Taylor Swift…whereas her sister Olivia was already in hospice at this age and could no longer walk, talk or hold up her head. None of Keira's every day, "normal" abilities would be possible without her receiving the treatment in Italy. A treatment she should have been able to have access to here in the U.S.

SB 250, which creates a right to try for individualized treatments for patients with life-threatening or severely debilitating diseases, can help prevent other families from facing the same situation we faced. The bill would give families the option to seek investigational personalized therapies right here in Kansas rather than having to drop everything and move overseas.

Please protect the right to try to save one's own life by supporting SB 250.

Sincerely,
Kendra Riley