Senate Health & Human Services

04/10/2025 01:30 PM

HB25-1270 Patients' Right to Try Individualized Treatments

Typed Text of Testimony Submitted

Name, Position, Representing	**Typed Text of Testimony**
Bridget Dandaraw-Seritt For themself	Honorable Senators, Today, I'm urging your support for the Right to Try bill, HB25-1270. I have multiple illnesses, but one of the most pathological is Ehlers-Danlos Syndrome. As I've gotten older, this genetic rare disease has dissolved and ruptured nearly all my tendons and ligaments - and I do mean nearly all. I've lost the use of my hands, elbows, shoulders, knees, ankles, and feet. Several of my muscles are free hanging, and I can move my ribs around like I'm playing a game of Jenga. The worst is my spine that is no longer held together and decided to identify as a slinky. Last January, I needed a life-saving cervical spine surgery because my head was literally hanging off my neck compressing my brain stem and spinal cord. My bones decided to fuse naturally from C3-C7, but that pesky occipital joint just wouldn't stay still. Had this not been fixed, I would have stopped breathing within 3 months. My body clearly likes to live on the wild side. See the photo below of my fancy new neck hardware. Bow added to make it snazzy. There is no treatment for my illness. I'm only 50 and it's like the entire car just broke at once. Soon, all of my organs are going to start to break down. Ehlers-Danlos Syndrome (EDS) means my body makes some forms of collagen in a faulty manner. Collagen is in every organ and at some point my arteries and veins will start breaking, my heart will stop functioning right, and you don't even want to know what will happen to my digestive system. Think amoeba. Or Jello. Or maybe that ooze you made in 3rd grade science class. Fun, right? So what does this have to do with the bill? Well, research on my disease is becoming trendy finally. Hopefully, new therapies will be developed and start clinical trials in the future. I'm no longer a spring chicken, but I would

	jump at the chance to try a new therapy, even if it doesn’t work. Not just to try and stop my body from eating itself, but it could also help science so those coming after me don’t ever become like this. You see, my children and grandchildren all have EDS. Theirs isn’t terribly pathological now, but may become so as they age. I’d also like to see them grow up, graduate, and even have families of their own. However, right now my time is extremely limited. I want the right to be able to try new things, even if experimental. Please, please, pass HB25-1270 so anyone and everyone in my situation has the option to at least try. Cancer patients, sickle cell, spinal muscle atrophy, alternating hemiplegia of childhood, and all those rare disease patients deserve the choice. Thank you for supporting this bill. Bridget Dandaraw-Seritt Colorado Springs Founder, Advocates for Compassionate Therapy Now