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

RE: Vote Yes on SB 250

Dear Chairman Senator Beverly Gossage and Members of the Senate Committee on Public Health and Welfare,

My name is Elijah Stacy. I am 23 years old, and for as long as I can remember, I have been fighting an uphill battle against Duchenne Muscular Dystrophy (DMD), a progressive and fatal genetic disorder. At just six years old, I was diagnosed with this disease that would come to define my daily struggles but not my spirit. By 11, I lost my ability to walk. Today, I am fully dependent on a power wheelchair and face the relentless challenges of this disease every moment of my life.

DMD is a thief. It steals the ability to run, walk, hug loved ones, and eventually even to breathe. It is a disease that robs individuals of their independence and families of precious time. I have watched my own body weaken over the years, losing my ability to lift my arms and perform simple tasks. Despite this, I have worked tirelessly to defy expectations, founding a nonprofit called Destroy Duchenne at the age of 15 to fight for patients like me.

But my fight is personal in ways that words can hardly convey. I've lived through the devastation of this disease, not just in my body but in my family. My younger brother Max passed away from DMD at the age of 14. My youngest brother is now 17, battling the same relentless condition. I've watched my parents pour everything they have—physically, emotionally, and financially—into supporting us while dealing with the unbearable pain of knowing the future DMD typically holds.

My journey is filled with moments of profound grief and resilience. It's also marked by hope. As a biotech consultant and someone deeply involved in the field of medical innovation, I see the incredible advances being made in personalized medicine. Treatments now in development hold the potential to preserve muscle function and fundamentally change the trajectory of rare diseases like DMD. But hope for patients like me and my brother is often trapped in the bureaucratic red tape of the FDA's outdated regulatory system.

Time is a luxury I don't have. The average lifespan for someone with Duchenne is 25. My muscles continue to waste away, and every day brings the possibility of losing more function. Many other patients face even greater urgency—some are mere days or weeks away from losing their fight. That is why I urge you to support the Right to Try for Individualized Treatments Act (Right to Try 2.0).

This legislation would give patients with life-threatening or severely debilitating illnesses access to investigational treatments customized to their genetic makeup when all approved options have been exhausted. It empowers patients and their doctors to make critical decisions without unnecessary government barriers. It is about giving people like me a fighting chance.

Imagine watching your body deteriorate while knowing that promising therapies exist but are inaccessible due to years-long regulatory processes. I don't want to spend my last years hoping—I want to spend them living. With Right to Try 2.0, patients like me can gain timely access to these treatments, potentially preserving muscle function, extending our lives, and improving the quality of every day we have left.

Please understand that this is not just about me. It's about the 30 million Americans living with rare diseases, 95% of whom have no FDA-approved treatment options. It's about the families, the caregivers, and the loved ones who fight alongside us. This legislation has already been passed in six states, and it's time for Kansas to lead in this life-saving effort.

I ask you to vote yes on SB 250 and give patients like me the opportunity to fight for our lives. We don't want pity; we want a chance. A chance to pursue hope. A chance to live.

Thank you for your time and consideration.

Sincerely,
Elijah Stacy
Founder, Destroy Duchenne
Bestselling Author and Patient Advocate