

Chairman Lampton, Vice Chair Barhorst, Ranking Member Miranda, and Members of the House Insurance Committee, thank you for the opportunity to provide written proponent testimony on House Bill 291.

Little Hercules Foundation (LHF) is a registered, non-profit 501(c)(3) organization based in Dublin, Ohio. Little Hercules Foundation got its start in January 2013 when three moms, two of whom had sons diagnosed with Duchenne Muscular Dystrophy, decided to host events to help fund research. Since then, Little Hercules Foundation has grown into much more. We focus on improving the lives of those diagnosed with Duchenne Muscular Dystrophy through four main pillars: Advocacy, Awareness, Family Assistance and Funding Research.

My testimony is to express LHF's support of HB 291, which will prohibit non-medical switching of drugs during a benefit plan year once a patient has already made sure the prescription drugs they need are on formulary and budgeted for their copays and out-of-pocket costs.

Duchenne Muscular Dystrophy (DMD) is a rare, progressive, muscle-wasting disease in which those diagnosed are unable to produce dystrophin, a protein essential for the repair and stability of muscle fibers. Without dystrophin, muscle cells are damaged and replaced with connective tissue. DMD is the most common and leading fatal genetic disorder in children, affecting approximately 1 in 5,000 male births with an estimated 300,000 sufferers worldwide today. Currently, there is no cure; DMD is 100% fatal.

DMD is generally diagnosed between the ages of 3-5 when boys start showing muscle weakness and delayed development. It is then that parents or caregivers notice some early signs of DMD such as speech delay, enlarged calf muscles, and challenges with physical tasks such as running, stair-climbing, riding a bike, and balance. Nearly 30% of the time, boys with DMD also have neurological disorders such as autism, ADHD, and other behavior or learning disabilities that make it difficult for them socially and emotionally in school. This stems from the fact that a small amount of dystrophin is located in the brain.

As the disease progresses, boys living with DMD typically lose the ability to walk between the ages of 8-12. Physical activity can be greatly limited throughout childhood. Parents and caregivers may choose to avoid some physical activity during early stage in order to preserve good muscle fiber for as long as possible. In addition to skeletal muscle strength and function, care for DMD includes a focus on heart and lung preservation. Young men living with Duchenne typically lose their lives in their mid-20's from heart or lung failure, although it is important to note that progression can vary greatly.

This means a regimen of prescription drugs, treatments, and therapy that all works together for better patient outcomes. Any changes, especially a mid-year non-medical switch of a medication could have long term effects to the patient outcomes. Any changes, especially a mid-year non-medical switch of a medication could have long term effects on the patient's outcomes. Consumers are very savvy and choose plans at the beginning of the year that will cover their needs throughout the plan year. HB291 would protect the consumer by holding the plans to their contractual obligations.

Thank you for your consideration in favorably passing HB291 out of the House Insurance Committee.

Kelly Maynard

President and Founder / Little Hercules Foundation