Chairman Huffman, Vice Chair Antani, Ranking Member Antonio and members of the Health Committee, thank you for the opportunity to provide written proponent testimony on House Bill 135.

Little Hercules Foundation (LHF) is a patient advocacy organization based in Dublin, Ohio that serves a national patient population. We focus on improving the lives of those diagnosed with Duchenne Muscular Dystrophy through advocacy, awareness, family assistance and funding research.

My testimony is to express LHF's support of HB 135, which will prohibit certain health insurance cost-sharing practices. Please protect the most vulnerable patients in Ohio from this predatory program.

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 and fatty tissue. DMD is typically diagnosed between the ages of 3-5 and affects approximately 15,000-20,000 in the United States. Currently, there is no cure; there are now 5 FDA-approved treatments which slow disease progression. Even so, DMD remains 100% fatal with an average life expectancy of early- to late-20s.

DMD affects all bodily systems. Upon diagnosis, patients start a bi-annual schedule for comprehensive, multidisciplined care. At these appointments, patients are seen by a neurologist, a physical therapist, an occupational therapist, a cardiologist, a pulmonologist, a behavioral/mental health provider, and occasionally a nutritionist if needed. Diagnosis kicks off a journey of trying to slow down the disease as much as possible, while providing quality of life supports. The care continuum involves orthotics, durable medical equipment such as manual wheelchair, power wheelchair, toileting/hygiene equipment, mechanical lifts, respiratory equipment, and more. Ancillary needs are handicapped-accessible vehicle, home modifications, home health aides, and school supports. **Treatments are only one piece of our complex care plan.**

DMD patients, like most rare disease patients, don't have options for generic medications. Copay accumulators and other cost-sharing practices target the one specialty drug that will provide treatment to those with DMD, making the out of pocket costs unsustainable for all other care required for patients with DMD to thrive. Patients have no say in the cost of treatments or whether a treatment is deemed a specialty drug, and should be protected from these unscrupulous practices. Please protect our patients by passing HB135 out of committee.