Chairman Lipps, Vice Chair Stewart, Ranking Member Dr. Liston and Members of the Public Health Committee, Thank you for the opportunity to provide written proponent testimony on House Bill 177.

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 177, 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 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 found primarily in boys. The dystrophin gene, which regulates dystrophin production, is located on the X-chromosome. Males, who each have one X- and Y-chromosome, are at risk for X-chromosome related disorders. Duchenne may be unknowingly passed from mother to child. Women can be carriers, but not manifest any symptoms likely due to their second, compensating X-chromosome. In approximately 35% of cases, however, DMD occurs because of a random, spontaneous mutation at formation of the dystrophin gene during pregnancy. Therefore, any child is at risk for having DMD.

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.

Copay accumulators target the one specialty drug that will provide treatment to those with DMD, making the out of pocket costs unsustainable for the other services needed for patients with DMD to thrive like steroids, hospital visits, doctor visits, and durable medical equipment. Please protect our patients by passing HB177 out of committee.

Sincerely,

Kelly Maynard

President and Founder / Little Hercules Foundation