

RE: Support H.766 to Protect Copay Assistance for Patients

House Committee on Health Care,

Little Hercules Foundation (LHF) is a patient advocacy organization based in Dublin, Ohio that serves a national patient population. LHF focuses on improving the lives of those diagnosed with Duchenne Muscular Dystrophy through family assistance and funding research to improve the quality of life of the patient and family, and engages on State Policy issues impacting the general Rare Disease Community through supporting advocacy and awareness efforts.

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. Although there is currently 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.

I am writing to provide input on behalf of the DMD community we serve. Many patients with DMD rely on copay assistance to access their medications and manage the overall expense of their treatment plans.

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 H. 766 out of committee to join the other 19 states, DC and Puerto Rico that have signed similar bills into law to ensure that benefit designs count the assistance provided towards the patients' out-of-pocket costs.

Thank you for your consideration,

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