Kelly Maynard – Mother to Jackson Maynard, 16

Wednesday, May 3, 2023

Chairman Huffman, Vice Chair Johnson, Ranking Member Antonio and members of the Senate Health Committee. My name is Kelly Maynard and I am from Dublin, Ohio. I am a mother to a 16yo son with Duchenne MD, and I also am the founder and President of Little Hercules Foundation. I am also a member of Ohio's Rare Disease Advisory Council.

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 our support of HC0021, which will add Duchenne muscular dystrophy to Ohio's NBS panel.

Duchenne Muscular Dystrophy (DMD) is a rare, progressive, muscle-wasting disease in which those diagnosed are unable to produce dystrophin. Without dystrophin, muscle cells are in a constant state of weakening and wasting. My youngest son, Jackson, was diagnosed with DMD when he was 5. At that time, he was walking and appeared completely healthy despite a few signs that we chalked up to developmental delays. At that time 10 years ago, there were no treatments for DMD and the future looked very different than it does today.

Today, we have 5 approved treatments-4 are mutation specific, 1 is a steroid. There are also 5 gene therapies in development, which we believe will drastically transform DMD from a terminal diagnosis to a manageable, chronic condition. One of those gene therapies was developed at Nationwide Childrens Hospital's Center for Cell and Gene Therapy, and has an expected FDA approval date of May 29 of this year.

So why should Ohio be the first state to add DMD to its NBS panel? We are at a unique crossroads with this disease, where the science is not only moving quickly but the opportunity to rewrite Duchenne history is within our grasp. Ohio is fortunate to have 3 Duchenne Certified Care Centers located at Nationwide Childrens, Cincinnati Childrens and Akron Childrens. As a direct result of the innovative research happening in our academic research hospitals, Ohio is positioned as one of the best locations in the world to receive the optimal care, access to clinical trials, and has attracted investment from the biotechnology and life sciences industries. Ohio is a state that has financially prioritized scientific research into rare and life limiting conditions and as a result, many families travel to Ohio from all over the country and the world for care and to hopefully get into a clinical trial. It only make sense for Ohio to lead the country in identifying babies with DMD at birth so we can get these newly-diagnosed babies into treatment and care as soon as possible.