Jason Dempsey – Testimony on behalf of Jude Dempsey

Wednesday, May 3rd, 2023

Good morning, Chairman Huffman, Vice Chair Johnson, Ranking Member Antonio and the members of the committee. My name is Jason Dempsey from Mason, OH and I'm here to talk about my 8-year-old son, Jude, who shares a name with a very popular song that you may have heard of, *"Hey Jude"*.

Jude and I have been advocating with the house of representatives and are very excited to see that newborn screening for Duchenne Muscular Dystrophy has made it in the health budget.

This is significant to us because we were not blessed with an early or easy diagnosis. In December of 2020, in the midst of a pandemic and the week before Christmas, Jude was diagnosed with Duchenne Muscular Dystrophy at age 5.

Long before that, we had noticed that Jude had missed some developmental milestones around 1.5 years old such as crawling, walking and talking. Although he finally hit those milestones, we noticed that at 2.5 years old he was toe walking. This started us on a 2+ year journey that included leg braces and intense physical therapy that was an effort to resolve his toe walking by improving range of motion and strengthening his legs and core.

After 2 years of PT and not getting the results we had hoped for, it was suggested that we have a CK blood test to rule out any type of muscular dystrophy. Sadly, this test did not rule out muscular dystrophy and we were sent to the neuromuscular clinic at Cincinnati Children's Hospital where Jude underwent a full evaluation and genetic testing. And that brings us back to the week before Christmas in 2020, when Jude was diagnosed with Duchenne Muscular Dystrophy at age 5.

Jude is now a 2nd grader and rides a mobility scooter at his school because he doesn't have the strength in his legs to walk to the lunchroom, to recess, or to the art class that he loves. I've often wondered if his daily life now could've been any different if we knew sooner?

What if we had tested him at 2 and a half when we noticed his toe walking? Or maybe if we had tested when he missed the developmental milestones at age 1 and a half. Or what if we had tested him as a newborn long before we noticed anything…

I know that if Jude was diagnosed at birth, we would have started him on muscular dystrophy protocols immediately and we wouldn't have spent over two years in physical therapy which was actually hurting him and damaging his muscles.

Right now, there are 5 gene therapies in development for DMD and one of them will go before the FDA on May 29th. We are so close to seeing a terminal illness turn into a chronic condition. With 3 world class neuromuscular clinics in our state (Cincinnati, Columbus and Akron), Ohio is primed to lead this nation by testing our newborns, making a quick diagnosis and getting our babies the treatment that they need.

In summary I'd like to make a reference back to that famous song that shares Jude's name. The lyrics of that song begin like this, ***"Hey Jude, don't make it bad, take a sad song and make it better."*** This is a life lesson that I am teaching Jude and that's why we're here today. I want to take our sad song and try to make it just a little better for someone else.

Please strongly consider keeping the newborn testing for Duchenne in the health budget so that we can ensure that no Ohio babies have to endure a long and painful diagnosis like Jude. Thank you for your time and I welcome any questions.