

Jason Dempsey – Testimony on behalf of Jude Dempsey

Thursday, March 23rd, 2023

Good morning, Chairman Carruthers, Ranking Member Liston and the members of the subcommittee. 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".

In December of 2020, the week before Christmas, Jude was diagnosed with Duchenne Muscular Dystrophy at age 5. This was where our DMD story began but not where our medical journey began.

When Jude was 1 and a half, his mother and I noticed that he was missing some developmental milestones. He was slow to crawl, walk and speak. After sharing this with his pediatrician, she soothed our concerns by saying we'd monitor it but sometimes this happens. When Jude has somewhere to go, he'll walk and when he has something to say, he'll speak. She was right. Although it was later than expected, Jude crawled, walked and talked.

When Jude was 2 and a half, we noticed that he was walking on his tip toes. Once again, his pediatrician assured us that "toe-walking" was somewhat common and while some severe cases require a heel cord surgery, most cases can be resolved with physical therapy. This started us on a 2+ year journey through physical therapy that included daytime leg braces, nighttime braces and even a 3-week period where Jude had to wear casts on his legs to help his mobility. This was all an effort to resolve his toe walking by improving range of motion and strengthening his legs and core.

Jude's physical therapist took a maternity leave, and we were assigned a new PT. This PT had ONE session with Jude and through her observation felt that maybe something else was causing Jude's troubles. She called our pediatrician and ordered some blood work to try and "rule out" any type of muscular dystrophy. My initial reaction to this order was ANGER. Who did she think she was? She only met my son once! We've been working for 2+ years to fix his toe walking! NOT MUSCULAR DYSTROPHY!

Without going into great detail on the specific blood test we did, I'll simply say that the results did not rule out Muscular Dystrophy. This result sent us to the neuromuscular clinic at Cincinnati Children's Hospital where Jude underwent a full evaluation and genetic panel tests. And with that, the week before Christmas in 2020, at age 5, Jude was diagnosed with Duchenne Muscular Dystrophy. I can share that my initial anger for that PT subsided. She figured out what was causing the issues that his mother and I had observed since he was small.

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 maybe if we had tested him as a newborn long before we noticed anything...

I'm not a doctor or scientist so I may never know. The professionals can help us understand that. But I wanted to share Jude's story with all of you and 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.**"

Friends, that's why I'm here today. I want to take this sad song and try to make just a little better. Please strongly consider support for the amendment that will ensure every child in Ohio is screened for Duchenne muscular dystrophy. Thank you for your time.