



# Jordan McLinn

*Duchenne Muscular Dystrophy*

*Indianapolis, Indiana*

***“We worked alongside many in the Duchenne community to fight for a treatment to receive accelerated approval. No one ever imagined the next roadblock would be access.” – Laura McLinn, Jordan’s Mom***

Just before he turned four, Jordan was diagnosed with Duchenne Muscular Dystrophy. Duchenne is a rare genetic muscle disease that affects skeletal, heart, and lung muscles, and is caused by a mutation in the gene that encodes for a protein called dystrophin. Without dystrophin, muscles are not able to function or repair themselves properly. The disease progresses relentlessly, starting with muscle weakness in the lower limbs that spreads to other parts of the body and results in an early death, usually before age 30. Until 2017 there were no available treatments for boys like Jordan.

At age seven, Jordan was fortunate to enroll in a clinical trial for viltolarsen, which aims to slow the progression of Duchenne for patients with a specific genetic mutation. In 2020, viltolarsen was approved through the accelerated approval pathway. Now 12, Jordan still receives weekly infusions, walks strong and tall, and has exceeded many of the assumptions made upon his 2013 diagnosis.

In addition to navigating her own son’s care, Jordan’s mother, Laura has done everything in her power to make progress for children and families with Duchenne and other health conditions that are too often devoid of hope. And while it absolutely shouldn’t be the case, Laura diligently continues the fight for access to treatments that stop disease progression and saves lives. Her advocacy efforts to raise awareness are important for holding payers accountable to the requirement that they cover treatments approved by the FDA under the accelerated approval pathway.

Because Duchenne follows the same trajectory, but at different rates, the value of time when it comes to diagnosis and access to life altering treatments is critical. The time that the accelerated approval pathway has provided to the McLinn family is positively invaluable.

