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Testimony for the House Oversight and Government Reform Committee Hearing

The Patient Perspective: The Devastating Impacts of Skyrocketing Drug Prices on American Families

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2154 Rayburn House Office Building Washington, DC 20515

Good Morning Chairman Cummings, Ranking Member Jordan, Members of the Committee and anyone else who may be listening. It's an honor to be here with you today. My name is Laura McLinn. Most people know me as, "Jordan McLinn's mom" though. I come here today simply as just that... Jordan's mom. The words I speak are my own and come straight from my heart.

Jordan is my amazing, funny, kind, compassionate, faith filled little boy. He's not here today because he's at MDA Summer camp, having the time of his life...as he should be. Jordan is also in a race with the clock for his life though... because just before his fourth birthday, a doctor told us he has a rare and fatal muscle wasting disease called Duchenne Muscular Dystrophy.

According to the natural history of this disease, Jordan has already lived about half his life at just ten years old. DMD affects about one in every 5,000 boys and over a short time robs them of their ability to do the things most boys love to do... walk, run, play, climb, participate in sports, ride bikes, use the bathroom independently, feed themselves, dress themselves. Eventually even the strength to hug their moms is ripped away. Jordan gives the best hugs ever and the thought of him not being able to do that is just NOT okay. The heart and lungs are eventually affected which leads to a very young and devastating life expectancy.

Because of innovation and laws that Congress has passed over the years, I'm here today to tell you that my Jordan now has HOPE. He is the epitome of HOPE. He is defying the natural history of this disease and he is a direct participant in helping to create HOPE for others.

About 2 ½ years ago Jordan became one of 16 “lucky” boys in North America to be accepted into a clinical trial for a therapy designed to slow the progression of DMD. He’s made weekly trips out of state to receive infusions without a single complaint... EVER. During this time, we have noticed that Jordan is doing things that we were told a ten year old child with Duchenne wouldn’t typically be able to do... he’s still walking quite well, playing outside for hours, climbing stairs in a normal way. He’s dancing, running and jumping into pools and catching balls. Keep in mind Duchenne progressively robs boys of these things. Just last week, a research team showed me MRI images of some of Jordan’s muscles and they told me they did not look like the images of a person with muscular dystrophy.

When Jordan was first diagnosed, there was no clinical trial he could participate in. Now, there are multiple treatments in the pipeline. It’s absolutely incredible how fast the science is moving but Jordan and other patients like him cannot afford to see this innovation slow or stop. I DESPERATELY NEED scientists, doctors, and drug companies to continue to develop drugs for my son and the millions of others with devastating diseases and for that reason, **we must continue to encourage and reward innovation.**

Because of bipartisan work that many of you have been a part of over the years (fast track designation, accelerated approval pathway, innovative trial designs, etc) I expect that Jordan’s drug will be approved soon. When that happens, it will probably be expensive, as are most drugs for rare diseases. These aren’t old drugs that have been around for years though. **Let’s please be careful in these conversations about drug pricing to not mesh the two.** Innovation is expensive... and it’s also the only thing that’s going to help ensure that boys like my Jordan can be a part of the first generation to change the natural history of these devastating diseases. If we lose innovation we lose the most valuable thing that we can’t put a price tag on... human lives. We cannot afford to let that happen.

As you work to tackle the issues of access and affordability of existing treatments, treatments currently in clinical trials and treatments and cures yet to be discovered, I implore you to do so carefully and remember that one size does not fit all. We can’t afford to discourage those discoveries and the development of new therapies. If we had done that 10, 20 years ago, Jordan wouldn’t be benefiting from the treatment he is today.

Back home in Indiana today, parents are gathering to pick up their kids from MDA Camp and hear all about their adventures. I won’t be there for Jordan. Instead, with his blessing, I came here to share with all of you – and anyone else who will listen – the critical importance of driving forward the promise of new, more and better treatments for

all those who wait. I can't wait to get home to hug him tonight and with your help hopefully I'll never have to stop receiving those amazing hugs.

Because Jordan can't be here with me today to speak for himself, I want to leave you with his favorite quote. His life verse. It's from Jeremiah 29:11 from his favorite book and it says, "For I know the plans I have for you, declares the Lord, plans to prosper you and not to harm you. Plans to give you **HOPE** and **FUTURE**."

Thank you today, from the bottom of my heart... for wanting to make HOPE tangible, for caring about the FUTURE of millions of patients depending on you to keep innovation alive and for also caring about helping patients access those treatments, keeping in mind that one size doesn't always fit all.

I hope you will ask questions and I also welcome each of you to reach out to me personally after this hearing to continue this important dialogue. Let's work together... and keep doing the next right thing.