



“When you consider that the expected lifespan of a child with Duchenne is 20 to 25 years, days are like years for us. We’ve got enough roadblocks in our life, so having to mess around with struggling to get the right medicines approved is not something we enjoy or have time for.”

## Tim Revell and family | Leander, TX

Tim and Laura Revell’s precious boys both have Duchenne muscular dystrophy, the most common form of this genetic disorder, which causes progressive muscle degeneration and weakness. Twelve-year-old Timothy Revell was diagnosed with Duchenne on his second birthday. Coincidentally, Timothy’s younger brother, nine-year-old Andrew, was diagnosed on his fifth birthday. The boys receive some of their medicines, which include human growth hormone (HGH), as well as common drugs for osteoporosis, high blood pressure, ace inhibitors, and other heart medications, through a combination of private insurance and Medicaid. The process for getting medicines to the boys is complex and can be frustrating.

## Their Story

As a self-proclaimed ‘Dad advocate’ who volunteers with CureDuchenne and who refuses to take no for an answer when it comes to his boys, Tim believes that in his family’s case, time is life.

“As a parent of two children with special needs, I can totally understand the frustration of facing major roadblocks when trying to get a medicine through Medicaid. If my sons’ doctor said, ‘They need to be drinking milkshakes,’ and then state Medicaid came back and said, ‘No, they need to be eating cheese,’ I’d be furious.”

The Revells have to go out of state – to Ohio – for primary care for their sons. For Medicaid to grant access to the HGH they need – which their Ohio-based endocrinologist prescribed – prior authorization has to come through a Texas Medicaid-approved pediatrician. So, Tim must first go through an Austin-based pediatrician, who then has to fill out the prior authorization paperwork and jump through all the hoops to get the HGH covered.

“The whole process is time-consuming and somewhat overwhelming. In addition, at the end of last year, we had to switch one of our doctors because the pediatrician we had gone to for years dropped her Texas Medicaid affiliation because the hassle was too great and the payout was minimal.”

Despite these many challenges, Tim continues to work hard to provide a normal upbringing for his sons, and strongly believes that the doctor and the patient, or his or her advocates, should be the deciders in what medicines a patient should take.

**“We are our kids’ advocates. We do for them the things that they can’t do. There are only two responses you can have when faced with a critical health situation: either it’s going to take you down and overcome you, or you’re going to rise above it. I would encourage other families to rise above and step up and do what they can to push back when they see inequities in the healthcare system. I also feel badly about those patients who are stuck riding out the system and who aren’t aggressive enough to take the extra steps to push to get things done. As advocates, we also have to think about these folks and try to make sure we’re taking care of them.”**



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