

Thank you for nominating Rylan's Hope Foundation for a second time. We are honored to share with you who Rylan is and what Rylan's Hope is all about.

Rylan was born April 5, 2009 with extra fluid on his brain and the bones in his head prematurely fused together. Apparently, a one of a kind kid. With that came the seizures, mild hearing loss, low vision, wheelchair bound, nonverbal and g-tube feeding. Needless to say, he needed 24hr care.

He had many surgeries (brain, hip, reflux, g-tube and many more). He had specialized equipment and a lot of therapy! Physical Therapy, Occupational Therapy, Speech, Vision. You name it, he probably had it. We were desperately seeking ways to improve his quality of life. I found out very quickly that many of the things that could help him were not covered by insurance, no matter how many letters we wrote. They didn't care and we were at a loss.

When Rylan was 1 year old, we started doing hyperbaric oxygen therapy. We did over 100 dives and spent thousands upon thousands of dollars. Because Rylan was such a special kid, he needed all the special therapies that were not offered by the regular PT, OT or Speech therapists. Those costs were anywhere from \$50-\$150 per session. As a parent, when you finally see your child doing the smallest things that we take for granted with our typical kids, how can you stop? Therapy was priceless to us, even though our bank account did not agree.

Around age 6 Rylan's needs started shifting. At that point myself and his team of doctors felt a hospital bed would be beneficial to have. Not only for his health needs but also for his care takers being able to lift him up and do his personal care without injuring themselves as he continued to grow past 50lbs and 4 feet long. After fighting insurance for a year we were unsuccessful. Due to the cost of paying out of pocket, we never got one. This is just a drop in the bucket in the ocean of stories from one special needs kiddo and family. Talk to any parent with a special needs child and you will hear story after story that are just like mine.

In 2016 Rylan passed away at age 7. I was feeling lost and searching for my purpose again and a way to keep Rylan's name alive. That's when I realized that everything I went through with Rylan was setting me up to help other special needs families, who were also desperately seeking to improve their child's quality of life.

On April 5<sup>th</sup> 2017, what would've been Rylan's 8<sup>th</sup> birthday, Rylan's Hope Foundation was founded. We bring hope to families with special needs children from birth to 18 years old in the state of Wisconsin. Our mission is to raise funds for families that have children with disabilities in order to cover needed therapies, equipment and other disability-related expenses. We have helped 13 families totaling \$19,000. With things like respite, specialized therapy and even a wheelchair accessible van.

With the funds we'd be able to double the number of families helped. Because of the Coronavirus and navigating our new normal, which is something special needs families are

very familiar with, we will not be able to hold our main fundraising event as planned. This event brings in 90% of our funding each year.