#CHOOSEjoy
#NOTTODAYDRAVET #RYKERSRALLY

Ryker was diagnosed with Dravet Syndrome when he was 8 months old. He began having seizures at 5 months old and 3 months later, genetic testing pointed us to his final diagnosis. It was bittersweet. We were so glad to have an answer, but overwhelmed as we continued to learn more and more about the syndrome. Dravet Syndrome is a rare, catastrophic, lifelong form of epilepsy that begins in the first year of life with frequent and/or prolonged seizures. It affects 1:15,700 individuals, 80% of whom have a mutation in their SCN1A gene, which is the case for Ryker. Common issues associated with Dravet Syndrome include: prolonged seizures, frequent seizures, behavioral and developmental delays, movement and balance issues, orthopedic conditions, delayed language and speech issues, growth and nutrition issues, sleeping difficulties, chronic infections, sensory integration disorder and difficulty regulating body temperature, heart rate, blood pressure and other issues. As of now, there is NO CURE and current treatment options are limited. Ryker has tried several medications. He has tried a combination of 6 different daily medications, 2 vitamins and a supplement twice daily. Each medication has side effects and most aren't good for his overall health and development, but can be key to seizure control. We are confident that we have the right doctor overseeing Ryker's care, Dr. Linda Laux from Lurie's Childrens in Chicago is the best of the best. So, that's the short version of Ryker's journey thus far.

He amazes us daily. His smile is contagious. He brings so much JOY to our family. Therapists and doctors are always in awe of how alert and responsive he is considering all the medication he is on. He is happy (most of the time) and honestly, Ryan and I have decided that is our primary goal as we continue on this journey with him. To be happy. We #CHOOSEjoy and we pray that he is always able to #CHOOSEjoy.

May the God of hope fill you with all JOY and peace as you trust in Him. - Romans 15:13

We trust in God. We believe God has a plan for each one of us. This makes it easy to #CHOOSEjoy because we trust in Him. It's as simple as that.

I've often contemplated how people I know have made it through hard times. I haven't been in their shoes, but suspect it has something to do with their ability to #CHOOSEjoy. They find the silver lining, they make a concerted effort to find the good in all situations. In our journey with Ryker, he makes it easy to smile and laugh. He has given our family a different perspective on life, to appreciate the small things and to not take life for granted. Ryker has been blessed with 3 siblings - Kaitlyn, Brynna and Jake. It's not always easy to see Ryker at his worst, but they all come together to help whether it's comforting him, calling family for help when we need it, showing compassion for my husband, Ryan and I when we are tired and lose our patience, etc. Ryker has made our family stronger, and has taught us so much. Our family has a strong desire to support the work of the Dravet Syndrome Foundation. There is so much being done to find a cure and different treatment options. We are especially hopeful for gene therapies that could significantly help all that suffer from gene mutations. The challenge is, there is a significant lack of funding, thus the fundraising campaigns that our family has been initiating. Just know, we are forever grateful for all the love and support we have received.

We #CHOOSEjoy because there is good around us today and we have hope for better tomorrows. #nottodaydravet #rykersrally

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To support research for a cure, donate to the Dravet Syndrome Foundation by purchasing a #CHOOSEjoy merchandise at https://rykersrally.bigcartel.com.
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