

Harper Kay Huelskamp

Harper was born on July 9th 2014 with her twin brother Maddox. She was born with something called a hemangioma on her left arm. It was very large, and the doctors suggested that we have it removed because if it popped, it would bleed profusely and not be able to stop. She had it removed at about 6 months old. At one of her pre-op appointments, we realized that she was very fixated on something, and we could not get her attention. We did not think much of it because kids do get distracted by things very easily. A few days later, she did the same exact thing while she was sitting in her bouncer. This started to get concerning. So we decided to mention something to her doctor next time we went.

From there, our family doctor sent us to Dayton Children's hospital for a consult to see a neurologist. We were not getting the answers that we wanted, and felt like there was more wrong with her. So we decided to transfer her care to Nationwide Children's Hospital in Columbus, Ohio. There we met our wonderful neurologist Dr. Twanow. After many visits, many trial and error tests and medications, they came to a final diagnosis. Harper was diagnosed with Dravet Syndrome. This is a very serious and very rare seizure disorder. Dravet Syndrome is also known as Severe Myoclonic Epilepsy of Infancy.

She had her first grand mal seizure on April 22, 2015. She had just gotten out of the bathtub, and the temperature change from the warm bath to the cool air triggered a seizure. At this point in time, she had very minimal seizures and medications she was on. We immediately called the ambulance. From this point forward, we know that she was going to have a difficult journey.

Harper has been in and out of the hospital several times, many ambulance calls, many overnight ICU stays, and so many different illnesses that have triggered her seizures. She has stopped breathing in her sleep many times before, and still to this day has some trouble breathing.

Harper currently takes 12 different medications a day, has several hundreds of seizures a day, and is being followed by neurology, pulmonology, cardiology, behavioral pediatrics, nutritionist, dental, and occupational, physical, and speech therapists. This will be an ongoing fight that she deals with her entire life. We have an emergency plan for when she goes into different types of seizures, and different protocols we have to follow in certain situations. We also have it set up to where if we call the ambulance, they always have a care flight helicopter standing by if needed.

On a daily basis, we have to keep a very close eye on her because she has very many things she cannot tolerate. She cannot tolerate heat, sun, wind, bright lights, being too cool, loud noises, she is very sensitive to germs, too much stimulation, and drastic changes in temperature. We avoid taking her to places that involve any of these sensitivities such as restaurants, grocery stores, family gatherings, social events, and even outside. Harper stays inside most of her days because the weather is too hot or too cold for her body to handle because her body cannot regulate its body temperature. She cannot sweat, so when she gets too hot, her body temperature increases, and causes her to go into seizures. Our house has to stay at a specific temperature all day long to avoid temperature increases or decreases, and we avoid opening the windows due to the loud cars going by, the train, wind, and the heat or cold coming in.

Harper is a very happy and fun loving kid and always has a smile on her face. She enjoys every aspect of her life and the littlest things make her excited. Harper LOVES shoes, nail polish, makeup, slime, playdough, and watching her tablet. She also loves interacting with people when she gets the chance, even when she's at the hospital. She high fives and thanks everyone who comes into her room and is very cooperative most of the time. Harper is a survivor of this awful syndrome, and she fights it every day of her life. Even though she is not the typical 4 year old, she is our typical 4 year old and we couldn't be more blessed to have her in our life. She has really opened our eyes to what life has to offer and how precious it is.