Reid Michael Flannery

Reid Michael Flannery was born November 16, 2009 weighing in at 9lbs. 12 oz. he was HUGE! His first few months of life were very easy and he proved to be the perfect baby. He was sleeping through the night, meeting all developmental milestones, and just breezing through life. Things were great, until everything changed.

Reid was five months old when he had his first seizure, although it was months before we actually knew they were in fact seizures. It took nine different pediatricians before we were referred to a Neurologist to determine what was going on with Reid. You see, he didn't have what most of us would consider to be seizures. Reid would jerk his arm repeatedly, stare off into space constantly, and nod his head throughout the day. I knew something was wrong, but assumed he had some sort of TIC. After being admitted for neurological monitoring, Reid was diagnosed with myoclonic atonic epilepsy (jerk seizures with total body drop). We were told not to worry and that this would more than likely be something he would grow out of. He was put on a medication and sent home. A week later, Reid had a 25 minute Grand Mal seizure that was not responsive to paramedics attempts to stop it. He was admitted again for what would be one of many hospital stays over the next few years. The doctors were at a loss, but still felt confident that this was something he would outgrow.

I can still remember the moment that we got the call that Reid's genetic test results had come back positive for what the doctors had told us would be the "worst case scenario" or Dravet Syndrome. As a mother, I don't think you are ever prepared to deal with the devastation that follows a diagnosis like that. Reid was now a little over one year old and was having close to 1,000 seizures a day. We had identified several seizure triggers, which were fluorescent lighting, sunlight, body temperature change, textures, excitement, agitation, and water. It seemed the only way to keep him "safe" was to keep him inside our home, which is exactly what we did. We had been referred to another neurologist who specialized in advanced epilepsies to help figure out why after dozens of seizure medications, nothing was working. This doctor tested Reid for Dravet Syndrome and at least now we had an answer. Dravet Syndrome is a rare and catastrophic form of Epilepsy that develops in the first year of life and is progressive. This is not something that is outgrown and presents with multiple seizure types that are not responsive to medications. The prognosis for these children is poor as developmentally they begin to decline in the second year of life and there is a high death rate associated with the syndrome . Doctors are still trying to understand the disease, but have little knowledge of how to control it.

Reid is now five years old and the love of our lives. He is globally delayed, functioning at about a 1.5 year old level. Although the seizures are still relentless, we have learned to live life to the fullest and not allow Dravet Syndrome to dictate how we live. Reid attends a special school, where he continues to amaze us with the progress he is making. He loves letters, Cars, and Thomas the Train. With all of the positive, he still has a disease with no cure that can ultimately take him from us, so he sleeps with me every night as it is the only way I feel like I can make sure he is breathing. I live in constant fear that I will wake up and he will have passed during the night. This fear will never go away until a cure is found. We are so thankful for the research that is being done on Dravet Syndrome and feel certain that a cure will be found. We have participated in several research studies that will hopefully find the missing link and give peace to so many children suffering from these relentless seizures. Please visit www.DravetSyndromefoundation.org for more information on this disease.