



While looking through baby name books several months before our bundle of joy was to arrive, one name stuck out amongst all the others, Karley. There are a few different interpretations as to the meaning of her name, but made the decision based on the definition in our name book; womanly and strength. We envisioned bringing another intelligent, beautiful little girl into this world that will do great things for others and herself in her time on earth. Looking back, we are convinced that choosing Karley as her name is no coincidence; the Lord knows what he's doing. Even though it may appear that we've been punished, we trust that the Lord has placed this burden on Karley and our family for a reason. We do not fully understand why yet and we may not for some time, but someday his plan for her will be unveiled. Karley will have to be strong-willed and determined to overcome her life-long ailment and still achieve her full potential as a person. We will be there for her every step of the way and through our faith, unwavering love and support from family and friends, and the determination that's in her DNA, she will beat the odds and conquer her diagnosis of Dravet Syndrome.

Karley's first 2 years on earth have been difficult to say the least. She's been in and out of the hospital for status seizures, placed in ICU for loss of respiratory function caused by emergency antiepileptic drugs, and shuffled around daily for different doctor appointments and therapies. At one point, we contemplated staying next to the hospital because at the rate she was going, we would be back within a week. She's been to the ER and admitted to the hospital more times in her two years of life than most people are in their entire lives.

On May 30, 2013, after three months of torture waiting on the genetic testing results, we were informed that Karley has Dravet Syndrome. As one can imagine, we felt heartbroken, angry, confused, and in denial all in one wave of emotion. We say that we are dealing with it well, but those that have children with this awful disease know that we're not. Instead, we've been in a dark place since we found out, but we are getting better every day thanks to our faith, family, and friends. One thing that has helped us tremendously is to meet other families in the area and help out with a local fundraiser for the Dravet Syndrome Foundation. Raising money for Dravet research and dedicating ourselves to finding better treatment options are the only rays of hope we have to provide Karley and other children like her with a better quality of life.

Today, Karley battles myoclonic seizure attacks on a daily basis, occasionally has tonic-clonic episodes that require rescue medications to be administered followed by a trip to the ER, she struggles with her balance, walk & motor skills, and is constantly agitated throughout the day for reasons we don't fully understand. Her expressive and receptive language skills have actually regressed to a three month old level and she hasn't made any progress cognitively since she was nine months old. She is in ABA therapy three days a week for two hours at a time; which will be increased as she gets older. When she does sleep, it's easy to tell she isn't in a deep state of sleep, which is important for a child's development. Most nights she wakes up in the middle of the night and plays in her safety bed for a couple of hours before going back to sleep.

As anyone can see, every day is a struggle for Karley and children like her, which is why we will continue to pursue treatment options that have potential to provide her with a better quality of life.