



Grace was born a perfect baby a day before she was due to arrive and from the start she made our family complete and kept us on our toes. When she was 4 months old, Grace had her first seizure. It lasted 15 minutes and we didn't know what to do because no one in our family ever had a seizure, so we didn't even know what was happening. ER Doctors were told seizures were fairly common, and it would just be an isolated occurrence. We had no idea how wrong they were. It was just the beginning of Grace's seizure activity.

Grace had EEG's, MRI's, CAT scans and loads of blood work over the next few months. By the time she was 9 months old she had been in and out of the hospital and ER over 12 times. Her longest seizure lasting 49 minutes, we begged for answers and found none. Our neurologist suggested a genetic test to find some answers, and after a long battle with insurance we were finally given approval to test her when she was a year old. The diagnosis came at 14 months. Dravet Syndrome. Everything we read about Dravet answered so many questions like seizures triggered by warm baths, excitement and change of routine. These triggers all made sense, but at the time seemed like an impossible reason for a child to have a seizure. Over the next few months we struggled to find a medication that would control her seizures and give her a normal life. We have yet to find that "right" medication even though she is on 4 daily AED's and still watch her have seizures every day.

Grace is growing every day and our hope is that she will one day be seizure free and able to enjoy a happy, healthy life. We don't know what the future holds for our family but Grace's health will remain a priority until we can get a medication that will help her. We are running out of treatment options and Grace, along with other children in Texas like her; deserve to live a full life.