



Compassionate
Access for Epilepsy

Bellalynn

Bellalynn surprised us all when she came out with fire red hair and blue eyes. We all knew then she was a precious gift from God and she was going to change this world. But boy we didn't know what was going to happen!

October 14th, 2013 (Bella was 7.5 months old) I woke up to weird noises coming from her baby monitor and made my husband go check it. She was in a full body seizure, we started videoing it like the neurologist told us too and it didn't stop after a few minutes so we called 911. It ended up lasting 35 minutes and she stopped breathing on the way to hospital. I had to help the paramedic - but she helped Bellalynn start breathing again. After a lot more tests, they diagnosed her with epilepsy and started her on Phenobarbital. At this point they told us she would outgrow the seizures by age 2.

She was still having smaller myoclonic seizures so they added her on a 2nd seizure medicine. The week before Christmas they did a genetic test to see if maybe she had a genetic type of epilepsy, but it would take 3 months to get the test results.

March 11th, 2013 - The day we received the news that would change our lives forever - the neurologist called me, my sweet Bellalynn had Dravet Syndrome. My heart dropped. I still remember all of the dreams I had for her and it felt like they all went out of the door in that moment.

Dravet Syndrome is a rare and catastrophic form of intractable epilepsy that begins in infancy. Initial seizures are most often prolonged events and in the second year of life other seizure types begin to emerge. Development remains on track initially, with plateaus and a progressive decline typically beginning in the second year of life. Individuals with Dravet syndrome face a higher incidence of SUDEP (sudden unexplained death in epilepsy) and have associated conditions, which also need to be properly treated and managed.

Since Bellalynn's diagnosis she has had to fight hard for her life multiple times. Here is a recap of her battle with Dravet Syndrome (16 months):

- 22 hospital visits (most requiring more than a 1 night stay), 10 ground ambulance rides, 1 air ambulance ride
- 2 MRI's, 2 CAT Scans, 6 EEGs (one was 48hrs)
- Tried 2 medicines...currently on 3 a day
- Over 3,000 seizures lasting from 1 second to 3 hours status
- Followed by 3 specialists, along with physical, occupational and speech therapists
- \$382,239 in medical bills

We want the opportunity for our daughter to try CBD Oil. After she has been on 5 DIFFERENT STRONG seizure medicines AT FULL DOSES (currently on THREE), she is STILL having status seizures. We have almost lost her more than once due to these seizures that are lasting over 60 minutes. YES, I SAID 60 MINUTES! Can you imagine your child's body seizing for that long and not being able to DO ANYTHING! Can you imagine hearing the doctors saying "we have given her adult doses of all rescue meds" or "we may need to put her in a coma" or "keep giving her Ativan until she stops breathing or seizing"?

My daughter deserves the right to try CBD oil and have a normal life.

Wouldn't you want the same for your daughter?