C.A.F.E. TEXAS Compassionate Access for Epilepsy

Elissa

Elissa is our second daughter and was perfectly healthy at birth. At six months old she had her first tonic-clonic (convulsive) seizure. It lasted just over 30 minutes.

Soon after her first seizure, Elissa starting having myoclonic seizures upward to 30 a day, and they grew more frequent and intense over time. The tonic-clonic seizures also continued to occur at least monthly, with several lasting upward of 45 minutes in duration. Elissa was hospitalized 8 more times that first year for complications related to seizures. In February 2012, almost one year to the date of Elissa's first seizure, we received her genetic test results supporting a diagnosis of Dravet syndrome. While severe epilepsy and developmental delays are the primary problems associated with this disorder, there are a number of other significant health problems that often affect children with Dravet syndrome, including being at a higher risk for SUDEP (sudden unexplained death in epilepsy). As you can imagine, we were devastated, and all of what we imagined for Elissa's future disappeared.

Elissa is four years old. Obtaining a diagnosis in the first year had a huge impact on our ability for early intervention and we even had a few months that Elissa was seizure free. Unfortunately, Dravet syndrome is extremely resistant to treatment, and beginning in January 2014 her seizures became more frequent and she is now having tonic-clonic or other types of "big" seizures multiple times each week. Needless to say, this affects every aspect of her and our family's daily lives not knowing when the next seizure will strike. Her neurologist is trying a combination of two anti-seizure drugs now. They are failing. So, we are now going add a third investigational drug - that is not FDA approved – to her daily regime. After 2 drugs fail, the statistics tells us that adding a third drug will only have a 2-3% chance of success in controlling seizures. We worry constantly about the short-term and long-term side effects of the anti-seizure drugs (some of which are life threatening), and what next options will be given the limited treatment options currently available for kids with Dravet syndrome.

We want to try CBD oil given the extremely positive results that have been seen with its use as a treatment for Dravet syndrome - that is of course, in states where it is legal to use. To say it seems unfair that we can't provide Elissa access to a treatment option that may improve her quality of life because politics are administratively dictating her treatment is a profound understatement. We understand that the CBD oil is not a cure. But if it can better control her seizures, and without all of the horrible and severely impairing side effects – we should be able to try it. We are committed to doing everything within our power to ensure that our little girl receives all of the help necessary to improve her chances for a better outcome. We will work endlessly to advocate for research into more effective treatments and that those treatments are realistically accessible to patients. This is our way to choose hope and to share in the resiliency that Elissa reminds us of every day.