Patient Testimony/Proponent SB9

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Tracy Robles
2202 S. Old Manor Rd.
Wichita, Ks 67218
(316) 882-4367
Narwen000@hotmail.com

Thank you for the opportunity to testify in support of the Compassionate Care Act (SB9 and HB2011).

My name is Tracy Robles and I am testifying on behalf of someone who cannot speak for herself…my daughter Sofie. Sofie lives with me and her grandparents in Wichita. She is 6 years old, non-verbal, unable to chew food, feed herself, and is not toilet trained. In addition to having daily seizures she also has been diagnosed with autism, cortical visual impairment, and sensory processing disorder. Despite the lack of a functional communication system and in spite of her medical history Sofie is a vibrant and happy child.

At 18 months old Sofie was diagnosed with one of the most severe seizure disorders that exists…Dravet Syndrome. Dravet Syndrome is characterized by severe, intractable and refractory epilepsy. In addition to uncontrolled seizures it is accompanied by behavioral issues, autism, learning disabilities, mental retardation, sleep disorders, coordination problems, dysautonomia, and low muscle tone. These children are also high risk for SUDEP which is sudden unexplained death due to epilepsy. Current anti-epileptic drugs offer little relief and death rates are high.

Sofie had her first seizure at 18 months old. Prior to her first seizure she was a normal child that had met most of her developmental milestones on target. The first seizure was a tonic-clonic or grand mal seizure. It did not last long, but was not accompanied by a fever so she was admitted to the hospital for monitoring. During her stay at the hospital the seizure frequency increased and she began to have drop seizures also. After several days of observation Sofie was discharged and began her first anti-epileptic drug, Keppra.

Unfortunately, Keppra did nothing for her and the seizures continued. As the seizures rapidly built up in number, frequency, and duration, so did the anti-epileptic drugs tried. It is impossible for me to adequately describe what the next two years of life were like for her. There were many emergency room visits, frequent hospital stays, failed rescue doses of heavy drugs, and many combinations of anti-epileptic drugs tried. Still, Sofie was suffering drop attacks and tonic-clonic seizures multiple times EVERY DAY. For the next two years I watched as my vibrant daughter regressed back to infancy. She lost all speech and was only able to eat a liquid diet from a baby bottle. Between the medications she was on and the seizures the only thing that she did during this time was seize and sleep to recover from the seizures. During the time when most people are going through the “terrible twos” with their children Sofie did not laugh, did not cry, and was essentially in a vegetative state. The first time I heard my daughter laugh again was when she was having a seizure that triggered that part of her brain.

The medications that Sofie has been on come with side effects including: liver damage, kidney damage, loss of neurological function, hallucinations, muscle weakness, loss of appetite, depression, constipation, dizziness, drowsiness, gum overgrowth, changes in personality, chronic heart failure, rash, and ataxia among others. Sofie has even been put on a medication that is not approved for human use in the United States, but is used by veterinarians to control seizures in animals. Currently Sofie takes 6 prescription pills, a prescription stool softener, and multiple nutritional supplements daily. In addition to these she has a prescription for diazepam as her rescue medicine. Diazepam is valium. My 6 year old daughter has a doctor approved prescription for as much valium as she needs to stop her seizures, but she cannot have access to a plant.

I have had to make decisions on medications for my daughter based on whether liver damage or kidney damage is worse. I have had to resuscitate her when she stopped breathing due to her rescue medication. She has suffered black eyes, bruises, and other injuries as a result of seizures. She has trialed countless medications, diets, and natural therapies and still she continues to have multiple seizures daily. She has experienced about every type of known seizure including ones where she is conscious the entire time. During these she looks terrified, screams, pulls her hair out, and tries to injure herself. At times these seizure clusters last for over an hour. Seizure triggers for her include light, heat, illness, excitement, sleep, and bathing. She has so many seizure triggers she cannot even play outside unless the weather and the lighting are just right which is not very often. Last year, at 5 years old, seizure activity in the area of the brain where the pituitary gland is located caused Sofie to start puberty resulting in the need for additional medication to delay this change and an increase in seizure activity.

Medical Cannabis could help end this daily nightmare that Sofie has to endure. There are children who suffer from Dravet Syndrome that live in legal states, like Colorado, who have seen up to a 99% reduction in seizures from using edible oil made from high CBD low THC medical cannabis. I know that not every medication works for every individual and I am not claiming that this is a miracle cure for my daughters illness. All I am asking for is a chance…a chance to see if medical cannabis will help my daughter…a chance to drastically improve my daughter's quality of life.

Why should the state that we live in be the determining factor for whether or not Sofie gets the chance to thrive? I strongly encourage all of you to support Senate Bill 9 and House Bill 2011 and give not only my child a chance at a better life, but also the numerous other Kansans suffering from various health conditions that medical cannabis has shown to help. Thank you.

Sincerely,

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Examples of Self Injury occuring during seizure activity.

Some of the MANY Hospital Visits

Sofie Luella