

My Name is Jill Lane and I am speaking today in support of HB2152. Our son is Trenton Lane. He was born in January, 2003, a happy, healthy little boy. However, at ten weeks of age, he began having infantile spasms (a severe form of epilepsy). He was taken to Children's Mercy Hospital in Kansas City, where he was later diagnosed with a rare brain malformation called lissencephy, or smooth brain. This disorder left Trenton unable to speak, walk, talk, eat, crawl or do basic movements on his own. We were told that he would never be able to form thoughts or memories. As if that was not devastating enough, we were also told that he would suffer from a severe seizure disorder.

At ten weeks old, our son weighed a little over 8 pounds. He was started on high doses of steroids and a cocktail of benzodiazepine drugs to try and stop the seizures. We were told that if his brain went into status epilepticus, he would likely die. We were terrified to say the least. But, we also knew that these drugs carried their own terrible health risks. If given too much, he may die, given to little, he may die. The drugs affected his stomach, small intestine, and liver, not to mention his brain. Whatever development that could have continued was stopped completely by these drugs. He lost his ability to suck and therefore, he could no longer eat. At three years old, he had to have a feeding tube. After many attempts at trying different combinations of seizure medications, we still do not have control of his seizures. The type of seizures that Trenton has can end his life. As a matter of fact, they are the greatest health risk he has now.

A little over a year ago, we were watching a TV show that showed a little girl named Charlotte and she was taking CBD oil to stop her seizures. We felt that this may be a possibility for Trenton. As we did more research, we were amazed at the possibilities and potential benefits of this medicine. Not only could it help with his seizures, it could help with his chronic pain from scoliosis and his stomach issues. We would give anything to help our son, and we are hopeful that one day we will be able to try CBD oil. It could be the answer to our prayers. It would be amazing to be able to use an oil that not only controls his seizures, but also does little to no damage to his body.

We want the Kansas legislature to legalize CBD oil for the sole purpose of helping people with medical issues. If you had to watch your own child seize day after day, and literally waste away because the only solution to the seizures was also negatively affecting the rest of their body, you would want this. Please help us in our fight.

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