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SB 147 Hearing  
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My name is Beth Hartenstein Tolentino. I am testifying on behalf of our family as proponents of SB147. My husband, Elias, and I live in Manhattan. We have three adult children: Nicolas, age 26, and Sophia, age 21, who are with me today. Our middle child, 23-year-old Claire, is unable to be here, as is my husband.

Nicolas was born on Thanksgiving Day in 1989. I had a co-worker who also gave birth to a son just a few weeks earlier on Halloween Day. We loved sharing stories about what our boys were doing and how they were growing. But her son kept changing and learning, and mine didn't. I thought "Nick is just a week or so behind Jake." Then it became a month behind. And then three months behind. I finally threw away my copy of "What To Expect The First Year," a popular book for parents. It was too hard to read.

At 11 months of age, Nick began therapy for his "pervasive developmental delay of unknown etiology." We had no answers for why Nick was the way he was. Nick eventually learned to walk just before he turned three. He also learned a few signs and would occasionally imitate us. When his little sister, Claire, was born, we marveled at the mind-blowing speed at which even a very young "typical" child developed. When Claire was just a few months old, Nick's first seizure hit. Then one after another after another. For years and years.

Nick has been on every anti-epileptic drug there is. Literally. Once a patient has failed three AEDs, nothing is going to work. Doctors just keep throwing meds at them to see if something sticks. We toyed with trying the Ketogenic Diet when Nick was a child, but gave up the idea quickly. Nick was one of the first patients his surgeon placed a vagal nerve stimulator in. VNS never worked well. We've had countless trips to the ED for status epilepticus. We've given Nick Valium rectally and Versed intranasally to stop seizures. We've wanted to give *ourselves* valium and versed to stop our anxiety. There aren't enough rivers to hold the tears we've shed. We and all of our extended family and friends have pounded on the doors of heaven with our prayers. My husband -- trained as a minister -- has even anointed Nick with oil many times.

But the oil that has worked best for Nick is a hemp oil dietary supplement produced by CW Botanicals. This supplement was developed under the U.S. Agricultural Act of 2014, which includes a section on the legitimacy of industrial hemp research. We have given Nick Charlotte's Web hemp oil as a dietary supplement since April 2015. It has cut his seizures in half. We know the numbers because every month we submit data to the Interactive Network to Advance Scientific Knowledge: Web-based Longitudinal Observational Study of CBD use in Epilepsy.

Because the use of hemp oil still falls into a legally gray area in Kansas, we keep the hemp oil at our home and go to Nick's group home once a day to administer 3mL through his peg tube. We do not ask his group home staff to keep it onsite there nor does anyone other than our family administer it.

In addition to reducing the frequency and characteristics of Nick's seizures, we believe hemp oil's benefits played a part in protecting him on the worst day of our family's life. Early last summer Nick

sustained a fall and developed a massive subdural hemorrhage in his brain. May no one listening today ever look up at the bottom of a LifeStar helicopter flying overhead and know it is racing your dying child to the nearest neurosurgeon.

Nick survived the brain surgery to remove the clot from his brain. The surgeon said he would have only lived one more hour without surgical intervention. The next day, Nick was breathing on his own. In two days he was moved from neuro ICU to the floor. He ate and walked and within a week after his injury he was sent home.

He had no seizures during this time. He'd been on cannabidiol oil exactly one month.

Several studies have shown that cannabidiol has neuroprotective characteristics as well as anti-seizure characteristics. One study even describes them as providing "robust neuroprotection." Did CBD help Nick in this instance? Maybe. But we know for a fact it *does* help his seizures.

Please recommend this bill be passed.