

Hello, I would like to briefly introduce you to our son, Owen. He was born in November 2014 and shortly after birth was diagnosed with Congenital Disorder of Glycosylation type 1k, or ALG1-CDG, a rare genetic disorder. In fact, he was only the 17th known diagnosis in the world. It was just one of the many things that made Owen unique.

One of the primary manifestations of his disorder is hard-to-treat epileptic seizures. We spent months in and out of Stormont Vail and Children's Mercy receiving treatment, trying new things to help his seizures. Each medication came with its own sets of side effects. *Many of the medications made him so groggy that he could barely protect his own airway and required the support of a ventilator and mask to support his breathing while he slept.* Every decision about his medication became a discussion of how to balance the anti-seizure benefits with his ability to remain awake and as interactive as possible. At 6 months of age, he was on adult doses of 3 different anti-seizure medications as well as a highly specialized ketogenic diet for seizure control. Unfortunately, even that combination was not enough to slow the progression of his epilepsy, and he lost his fight on April 25th, 2015.

At the time Owen was alive, the legality of CBD oil in Kansas was questionable at best. Our doctors even mentioned to us that it could potentially help him, but the legal risk was not something we wanted to add to our lives when everything else was already so stressful. Also at that time, there were 2 other living children with the same disorder in the USA. Both of those families lived in states where they could access CBD oil for their children, and they both used it. One of them lived in a state where they could access CBD oil with only trace THC, and when asked how it helped her son, she states that she felt like it helped but not as much as she hoped. The other family was able to access low-THC CBD oil and felt like they had remarkable improvement using it, as they were able to wean their child to lower doses of the seizure medications which greatly improved her quality of life. The courses of treatment of our 3 kids used were identical, with the exception of the CBD oil. We did not use it, and our son lived to be 6 months old. *The child who used CBD oil with trace THC lived to be 2; and the child who used low-THC CBD oil lived to be 3.* Both of the other children were able to use *far less seizure medication and spent far more time outside of the hospital* than we did with Owen.

For us, using CBD oil was the last stone left unturned, and the ability to access low THC CBD oil would have been the Holy Grail as we sought to help our son. Unfortunately, we will live the rest of our lives wondering if something as simple as this might have given us more time with Owen and improved his quality of life.

Our family would respectfully ask you, our representatives and leaders, to think of Owen, Claire, Lola, and all of the others out there who could benefit from this change. Your support of HB 2244, Claire and Lola's Law, could improve the lives of countless families across our great state. Thank you!



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