

Kiley Klug  
~on behalf of Owen Klug  
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Written testimony as a proponent of HB2184

Wednesday, February 24th, 2021

Respected members of the Federal and State Affairs committee:

My name is Kiley Klug, and I humbly ask for your support of HB2184 on behalf of my 13-year-old son Owen. My husband Gavin and I reside in central Kansas with Owen and his two younger brothers. I am a junior high English teacher and my husband is a hard-working brick and stone mason. We are proud and practicing Catholics and have been married for 15 years.

My sweet, snuggly, laid back Owen unfortunately suffers from a rare, relentless seizure monster called Dravet Syndrome. He--in the past, at his worst--has struggled through up to 200-300 seizures a day. In his 13 years of life, he has endured 8 different surgeries, 9 failed pharmaceutical trials, and countless procedures, hospitalizations, and treatments. Other than a VNS implant and keto diet, no other conventional medical treatments have even come close to providing Owen any relief from his seizures; in fact, many of them made his seizures WORSE while exacerbating his condition with various side effects such as kidney, bone, and joint degeneration.

Thanks to Claire and Lola's Law, Gavin and I have found a combination of treatments that have improved Owen's quality of life by leaps and bounds. In combination with the VNS, keto, and regular chiropractic care, Haleigh's Hope hemp oil has given Owen his life back. On pharmaceutical medications, Owen slept all day, lost nearly all of the developmental and cognitive skills he once had, and constantly seized. I want you all to take a moment and think about this for a second: Owen used to sit up. He used to roll over and hold his own cup. Owen used to walk in a walker. Owen used to say 'mama,' 'dada,' 'no,' and 'yeah.' These sacred glimpses of our little boy's personality were stolen from us by pills. Haleigh's Hope gave us our little boy back. He's awake now. He communicates with us now. He smiles when we tell a joke or when his brothers talk to

him. And when he looks up at us intently with those big beautiful brown eyes, we feel his unconditional love again. I cannot begin to describe the joy and solace this safe, natural, non-psychoactive treatment has provided Owen and our family. With that said, some of you at this point may be asking, "If Owen is thriving on this medication, why are you here asking for more?" My short answer is puberty. Hormones have wreaked havoc on Owen's seizures, and he recently started struggling with new and more severe seizures. Dravet is a monster that keeps us guessing; it adapts, evolves, and becomes immune to treatments that initially work. We need the flexibility to explore different strains and ratios in order to find the combination that is the most effective at keeping Owen's seizures under control.

As Owen's mom, I would hope his story would be enough for you to support a comprehensive medical cannabis bill. However, I understand that for some of you it's not. So let's talk numbers. Gavin and I purchase Haleigh's Hope from an outsourced, reputable company. We spend a little over \$600 a year on a rescue nasal spray that--by the way--miraculously stifles Owen's violent convulsions upon contact. In addition, we spend \$300 per month on his hemp oil that he ingests twice a day. So in total, after taxes, shipping, and handling, we spend slightly over \$4,000 a year out of pocket on his medication.

Ladies and gentlemen, this is money that needs to remain in Kansas. As a teacher, I see firsthand the desperate need for these funds to remain with Kansas families through our healthcare facilities and specifically our schools. How can YOUR child's or grandchild's school district benefit from sufficient funding? My children's school district was and probably still is on the verge of closing because our rural district that spans four small communities cannot survive keeping four buildings open. In central Kansas, our communities live and die around our schools; USD 112 is also the district that employs me, so my livelihood depends on the survival of our school district. Furthermore, amidst this pandemic, expenses in schools have only become more prevalent.

To sum up, we need a better system. We have a win-win opportunity at our fingertips that could potentially help your cancer-stricken aunt or uncle, relieve my Marine veteran brother-in-law of vicious wartime nightmares, or provide aid to an innocent sick child whose family doesn't have the financial resources to afford out of pocket unconventional treatment options...all while vastly improving our struggling economic infrastructure. Let's do this. Let's help ourselves. It's time. Thank you.

Respectfully,  
Gavin, Kiley, and Owen Klug  
Odin, KS



