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Proponent of HB2152

Written Only

My name is Kiley Klug, and I am testifying as a proponent of HB2152. I live in rural central Kansas with my husband Gavin and our three sons. Gavin works two jobs, and though I am an educator by trade, I currently stay home to care for our three boys, two of which have chronic illnesses that require constant, efficient care. We are active Catholics. We are conservative. We are educated. But most importantly, we are parents. These boys are our cause, our reason for waking up in the morning, our happy place....it is our privilege to love them and loyally stand up for them whatever the cost. Our oldest son Owen unfortunately needs us to be his voice as well. He has had an extremely rough go, despite what his happy, laid-back persona might present.

Owen was born full-term following a normal pregnancy. Out of nowhere at 6 months of age, Owen began having seizures. And they haven't stopped since. At his worst, Owen had over 200 seizures in an 18-hour period (during an overnight video EEG) regardless of the four potentially fatal, fatigue-inducing medications he was taking at the time. On his best day, Owen still suffers from on average 10-20 seizures a day. I don't remember the last time this child went a day without a seizure. And unfortunately for him, seizures walk hand-in-hand with his development. Owen's development has--for the most part--digressed over the course of his lifetime. When Owen was a young toddler, he could hold his own cup, babble "mama" and "dada," smile appropriately, sit independently, and walk around clumsily in a walker. He currently cannot do any of these tasks independently; however, we will see glimpses of progress here and there depending on the seizure frequency at the time. Epilepsy is a prison Owen cannot escape. We look him in the eyes and we interact with him like any loving parent would do. He's present, he knows what's going on. He is just trapped and desperate to get out. Not being able to free your child of daily suffering is a desperate, torturous place to be as a parent. We research, pray, hope, and constantly communicate with other professionals to find the safest, most effective treatments available to free our child from this debilitating illness.

Gavin and I have followed doctors' orders diligently. We have tried 8 different pharmaceutical medications, some more than once. Owen is on his second attempt of the ketogenic diet, and he also just had his second vagal nerve stimulator surgery. What did we gain from all of these previously mentioned therapies? Mild seizure reduction at best, vomiting, constant liver, heart, bone and kidney testing, lethargy, edema, frequent blood draws, loss of skills, and multiple hospital stays...and the long-term damage to his vital organs has yet to be determined. Because we have no other choice, it's time we move on to alternative remedies.

Children like Owen who suffer from Dravet Syndrome have seen great success on hemp oil. According to a statement from the American Epilepsy Society regarding a recent Epidiolex

clinical trial administered by GW Pharmaceuticals, "DS patients had a 62 percent reduction in seizures and 13 percent were seizure-free." As a parent, these are encouraging statistics. Gavin and I are realists. We know hemp oil will not cause our son to start running marathons and saying his ABCs. We understand that every treatment has risks and rewards, and work for some and not all. Chances are this will not be the miracle cure we have been hoping for since Owen was diagnosed. However, we respectfully need you to understand our desperation to give our son the chance to try this supplement. A 62% AVERAGE REDUCTION IN SEIZURES. With NO chance of overdose. Without the lethargy and serious side effects. With not just the possibility of seizure reduction but also the possibility of improved development and daily skills. We are asking that you place this decision where it belongs. This is a doctor/patient issue, not a legislative one. Please give the medical professionals who care for these children the freedom to prescribe and utilize this medication.

I know many are concerned about the lack of FDA approval thus far. FDA approval is irrelevant, and I'll tell you why. The FDA does not require the approval of dietary supplements; they test for safety but do not require approval for efficacy. According to FDA.gov, "The law defines dietary supplements in part as products taken by mouth that contain a "dietary ingredient." Dietary ingredients include vitamins, minerals, amino acids, and herbs or botanicals, as well as other substances that can be used to supplement the diet. Dietary supplements come in many forms, including tablets, capsules, powders, energy bars, and liquids. These products are available in stores throughout the United States, as well as on the Internet. They are labeled as dietary supplements and may include plant materials....people use dietary supplements for a wide assortment of reasons. Some seek to compensate for diets, medical conditions, or eating habits that limit the intake of essential vitamins and nutrients." Committee members, hemp oil, by every form of the legal definition, is a supplement. Furthermore, many pharmaceutical medications that have caused tremendous harm and horrific side effects on Owen and many other children who suffer from intractable epilepsy have not always been, in fact, FDA approved. Examples of these include stiripentol and onfi, two of the most common AEDs prescribed by doctors for severe epilepsy. Owen was four years old when he was prescribed onfi. It wasn't at the time FDA approved. That didn't matter. His doctor proceeded to prescribe and increase his onfi dose to a dose that exceeded a maximum dose for an adult. The risk of overdose and death was present. Owen was a zombie who slept through half the day. So what's the difference? I'll tell you the difference. Hemp oil is safe. No one has ever overdosed on any form of cannabis, let alone non-psychoactive cannabis. Hemp oil can work when all pharmaceuticals have failed. Hemp oil allows children like Owen to be present.

We are well aware of the reservations. We are well aware of the supposed risks. And as parents who have fought to free our children from this pharmaceutical, epileptic fog, we are in all honesty tired of the reservations and risks. To us, the real risk is not providing an opportunity to help these children. The real risk is suppressing, denying, or stalling this bill and allowing these children to continue to suffer. Passing HB2152 would open a whole new world of possible strains, varying chemistries, and potential remedies for these children. Be the person who helps these kids. We are pleading for you to help us help them. Thank you.