We both grew up in Kansas, and Kansas will always be our home.

After college, we met and moved to New York City. After becoming engaged a few years later, we made a decision to start our lives together as a married couple, and to begin our own family, in Kansas, near to our own families.

Upon moving back to Kansas in 2007, Ryan began teaching at a rural high school near Topeka, and Kathy worked at the University of Kansas. We are both hard working, community-minded citizens.

In June of 2011 we had the absolute joy of welcoming our son and only child, Otis, into the world.

In September of 2011 Otis had his first seizure, and Otis received the diagnosis of Infantile Spasms, a catastrophic form of infantile epilepsy. Since that day, the seizures have only progressed, and our own lives have become geared toward stopping those relentless seizures.

Otis has hundreds of seizures a day. These seizures have left him developmentally disabled and completely dependent on us in every way, even in the most basic activities of daily living. The constant seizure activity has prevented Otis from being able to learn, develop, and reach milestones like most typically-developing kids. Although Otis is 3 and-a-half years old now, his developmental level is that of a 6-11 month old, at best.

Otis has been seen by neurologists and epileptologists in Kansas City, St. Louis, the Cleveland Clinic, and Denver. He has tried over a dozen different medications in order to stop his seizures. None of them have provided any seizure relief. In fact, most of these pharmaceuticals have caused negative side effects, from sleeplessness, anorexia, impaired cognition, zombie-like "stoned" states, and severe agitation and rage, to a life threatening cardiomyopathy. In 2013 he had surgery to implant a device, a vagal nerve stimulator (VNS) that would give him shock therapy around the clock. He has also suffered through a very strict diet for 2.5 years that, in combination with the mineral-leaching anticonvulsant pharmaceuticals, left his bones weak, leading to a fractured femur at 2.5 years of age.

Nothing worked to control Otis' seizures, or give him a better quality of life. In fact, it began to seem as though these treatments were working against him.

Our day to day was living seizure to seizure. Days were peppered with seizures and frustration, and nights seemed to be never-ending. Otis did not have a bedtime, and not for our lack of trying. Due to the frequency of his seizure activity, he would fall asleep at 7pm one night and 2am the next night, and naps were few and far between. Most of his seizures came in clusters at night. He would be asleep for 2-3 hours and wake up with a cluster of seizures that usually lasted about an hour, then go back to sleep for an hour or so only to be up again for another hour of seizures. This continued throughout most of the night, every night. There is nothing we have experienced more heartbreaking than helplessly holding our child night after night as he seizes uncontrollably.

Our team of neurologists told us that, having been failed by all else, our last option was to remove or disconnect half of Otis' brain. Because EEGs, MRIs, and a PET scan have not been able to identify a focal point in Otis' brain where the seizures are originating, his seizures are considered to be generalized, meaning that they appear to come from all over his brain. Because of this, the hemispherectomy surgery is seen as a last resort. Surgery is not only a risky and permanent last resort, but the chances of success are not good—less than 50% chance of any seizure improvement at all, for a child who suffers over 500 seizures each and every day. Those odds are just not good enough for our son. We agreed with our doctors, brain surgery would be a last resort.

In the fall of 2013 we began to hear about how medical marijuana has helped children with severe, drug-resistant forms of epilepsy like Otis. At first we were skeptical, but after talking to some of these parents we knew that we had to try medical marijuana before we removed half of our son's brain.

Our options at this point were: 1. Permanently cut out half of our child's brain with no guarantee of success, short or long term, or 2. Try a medicinal plant that has worked well for other children like Otis.

We decided to try medical marijuana.

The decision was easy; however, the act of providing this medicine to our son was far from easy. In order to give our son a chance at a better quality of life we gave up our home, our jobs, our support system, and being close to those we love.

Because of current laws in Kansas--our home--we had to uproot our lives and move to another state, Colorado, on the hope that medical marijuana would help Otis. It was difficult and continues to be difficult to be so far from our home and the ones we love, but we would do it again in a heartbeat to provide a better life for our son.

Since beginning high CBD, low THC medical marijuana treatment, Otis' quality of life has greatly improved. He now has a regular bedtime of 8pm and sleeps anywhere from 4 to 9 hours *in a row* for the first time in his life, which has helped us all. Over the course of the 8 months he has been on the CBD treatment, we have been able to wean him over half way off of his remaining anti-epileptic drug, a benzodiazepine called ONFI (or Clobazam), known to be more addictive than even heroin. He has improved cognitively and developmentally. He has learned to drink from a straw, assist in sitting up, assist in feeding himself, army crawl to a desired object, and use his previously unused right hand…just to name a few. He has become clearer and more alert, making more eye contact, interacting more with us, his therapists, and his peers at preschool. He now giggles and reacts to being tickled. He continues to become stronger and stronger, weight-bearing on his legs and left hand. And the best thing of all…he smiles and laughs each and every day now! All of this without the negative, and many times dangerous, side effects he suffered from the 12 FDA-approved "safe" anticonvulsant medications, steroid therapies, and ketogenic diet that had been prescribed to him—and failed him--previously.

Unfortunately, despite the many and growing cognitive and developmental gains we have seen over the course of the past several months, Otis has not yet experienced the seizure control that many of his new friends out here in Colorado have experienced. Fortunately, there are still many more medical cannabis options available for us to try, and in this, we have been given a renewed sense of hope for Otis' future. Otis is experiencing a better quality life than he has ever experienced, and it is thanks to medical marijuana.

We are dealing with a difficult diagnosis for which there is no cure. Our day to day is hard, but we are managing…and managing well, we think, despite the many obstacles with which we are faced. But to add to the mix a move away from our home, our families, and our support system…it's not right. As parents of a child with severe special and medical needs, we've got enough work cut out without also having to start our lives over in a new place. We love Kansas, but there is no justice in this. We should be allowed to live in our home and be around the people that we need most during the most difficult trial of our lives. It. Is. Not. Right.

We ask for compassion. We invite you come spend time with us. We welcome you to sit with us as we hopelessly hold our child as he seizes…and see why anyone in our situation would do the same.

We ask you to please imagine, if you can, being in our shoes. As a parent, imagine being told by your child's doctors that they have tried everything, that nearly all medical options except for a very risky brain surgery—one that has, at best, a 50% chance of providing any relief at all--have been exhausted, that there is next to nothing left to be done to heal your child, who is not even 3 years old.

Imagine the fear and absolute desperation you would feel in that situation. Imagine what it is like to sit up with your child, at midnight, 2 a.m., 4 a.m., holding him close to you, helpless as he seizes over and over and over again. Crying, praying, cursing, whispering, hushing, and singing to your child, absolutely helpless, between your own barely contained sobs.

Please ask yourself what you would do, having exhausted all available medical options. Who would you turn to for help? Would you just throw your hands up, toss in the towel and give up on your child? No, you wouldn't. Of course you wouldn't.

You would continue to fight for your child, endlessly, relentlessly, through fear and anger and sorrow and exhaustion, doing everything and anything possible, pursuing anything that offers the slightest possibility of relief for your child. Because if we parents don't fight and advocate for our children, who will? We truly believe that if put in our shoes, any other parent would do the same for their child.

It is our hope and plea that the individuals with the most power and the most influence within our state will have the courage to stand up and do something to help our son and other children in Kansas like him, because we are far from being the only ones—to hear our stories, to have empathy and compassion for these medically fragile children, to give us another option when all else have failed us.

As native Kansans and parents of a child who suffers from progressive, drug-resistant epilepsy, we ask that our Kansas legislators have compassion for our family, for our sweet son Otis, and for other Kansas children like him. It is our hope that Kansas legislators will develop a well-regulated medical marijuana program that allows for research, local cultivation and testing of this promising, plant-based medicine, direct access for patients in need. If nothing else, we ask simply for reciprocity for families like ours, so that we may legally cross the state line into Kansas, with our son's medicine, to visit our families without fear of being prosecuted.

We thank you for hearing our story.

We would be happy to answer any questions you may have about Otis our experience.

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