Patient Testimony/SB9 Proponent

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My wife Sarah and I have lived in Prairie Village for the past 16 years. I am a practicing architect with Populous in Kansas City and have been working in the area for the past 21 years. Sarah and I have three wonderful children, Eli, who is almost 12, Mira, who is 9 1/2, and Jonah, who is 6 1/2. We live in quaint 1950's ranch home (as does most of the district) right next to McCrum Park in Prairie Village. We love this community and want to avoid having to move out of the state to help my daughter.

My daughter Mira has a debilitating form of epilepsy called Dravet Syndrome. This causes her to have constant daily seizures. Because of the complexity and severity of her disorder, she also has been diagnosed with West Syndrome, Lennox-Gastaut Syndrome, atypical Rett Syndrome, and a host of other variations revolving around catastrophic epilepsies. Unless you live it every day, no one can understand the implications of raising a child with a fragile, complex neurological condition and the impact it has on us as a family.

Mira has been having daily seizures since she was 11 weeks old. We have never been able to gain full seizure control since that time. She has relentless tonic-clonic and myoclonic seizures daily, seizures that have limited her development to that of a 3 month old infant. She is non-ambulatory, non-verbal and non-communicative.

Unfortunately, Mira has exhausted nearly every acceptable pharmaceutical option, diet, and therapy in an effort to halt her seizures. She is currently on a trial of Vimpat (lacosamide) which is the 22nd medication trial she has tried. We have tried some of these medications twice. Just to give you an idea of what pharmaceutical and diet options she has tried, chronologically they are:

Phenobarbital
ACTH (Adrenocorticotropic Hormone injections)
Pyridoxine/P5P
Depakene (Valproic Acid)
Zonegran (Zonisamide – tried twice)
Clonazepam (Klonopin)
Keppra (Levetiracetam – tried twice)
Topamax (Topiramate)
Sabil (Vigabatrin)
Trileptal (Oxcarbazepine)

Diamox (Acetazolamide)
Felbatol (Felbamate)
Lamictal (Lamotrigine)
Ketogenic Diet
Modified Atkins Diet
Lyrica (Pregabalin)
Zarontin (Ethosuximide)
Banzel (Rufinamide)
Tranxene (Clorazepate)
Onfi (Clobazam)
Vimpat (Lacosamide)

Many of these medications have helped thousands of children with catastrophic epilepsies, but unfortunately none of them have helped my Mira. In fact, many of them have exacerbated her symptoms, causing increased seizure activity and irritability among other things.

I am a well-educated and very informed parent. I research all of the time. In the last 9+ years, I have read thousands of abstracts, articles, and studies – anything that could potentially help my daughter. In 2009, I began to read stories of medical cannabis and the success of cannabis oil in helping some children with Dravet Syndrome in Colorado. Since that time, I have watched my child suffer thousands upon thousands of seizures with no relief. When will the state of Kansas give Mira and our family a chance at a better life? Will we be forced to become another refugee from the state of Kansas, uprooting our children and our lives, just to gain access to a medication that could save the life of my daughter Mira? We should not be forced to make that decision.

I am urging you to not only recognize Senate Bill 9 (SB9), but to also pass this critical legislation. My daughter continues to suffer with no viable treatment options remaining.

Thank you.

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Mira's blog can be seen at missmiras.blogspot.com.