

March 9, 2016

Marc Bertolino, AIA, LEED AP
4708 West 70th Street
Prairie Village, KS 66208
913.526.7286 cell
marcus1988001@yahoo.com



My wife Sarah and I have lived in Prairie Village for the past 17 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 (13), Mira (10), and Jonah (7). We live in quaint 1950's ranch, 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 Lennox-Gastaut Syndrome, which causes her to have consistent, daily seizures. Because of the complexity and severity of her disorder, she also has been diagnosed with West Syndrome, atypical Rett Syndrome, and a host of other variations revolving around catastrophic epilepsies. 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, unless you live it every day.

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 every single day; seizures that have limited her development to that of a 3 month old infant. She is non-ambulatory, non-verbal, and non-communicative. On an average day, she will have hundreds of myoclonic seizures, along with 1-2 involved, tonic-clonic seizures. Lately, her seizures have increased to the point where we have had to administer rescue medications more time in the last 12 months, than we have in the last 9 years combined. Mira has episodes where she has multiple tonic-clonics, sometimes 7-8 massive seizures within 30-45 minutes, which requires us to intervene with rescue medications, in an attempt to stop these clustering seizures.

Unfortunately, Mira has exhausted nearly every acceptable pharmaceutical option, diet, and therapy in an effort to halt her seizures. She is currently taking Lyrica, which is the 23rd medication or dietary 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 (Adrenocorticotrophic 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 – tried twice)
Zarontin (Ethosuximide)
Banzel (Rufinamide)
Tranxene (Clorazepate)
Onfi (Clobazam)
Vimpat (Lacosamide)
Prozac (Fluoxetine)

If you have ever venture to read some of the horrific side effects of these medications, you would be mortified about giving them to your child. Yet, these are routinely prescribed by neurologists and doctors, most of the time without fully understanding the ramifications of the toxic byproducts that are being introduced to your child's delicate systems. Most of manufacturers of these medications also have yet to conduct a single pediatric trial, which is frightening, when they are so easily prescribed. The efficacy of all of these medications in Mira's case, has been 0%.

Please understand that I am not anti-pharmaceuticals. Many of these medications have helped thousands of children with catastrophic epilepsies, but unfortunately, none of them have helped my daughter. In fact, many of them have exacerbated her symptoms, causing increased seizure activity, severe lethargy, and irritability, among other things, in addition to having no impact on her daily seizure activity.

I am a well-educated and very informed parent. I research all of the time. In the last 10 years, I have read thousands of abstracts, articles, and studies – anything that could potentially help my daughter. In terms of remaining options, I only recognized the potential of medical cannabis as a viable treatment back in 2009. Since that time, I have watched my child suffer thousands upon thousands of seizures, while legislation in the State of Kansas has been at a complete standstill.

I am urging you to not only recognize Senate Bill 147 (SB147), but to also pass this critical legislation. My daughter continues to suffer, with no viable treatment options remaining.

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

Sincerely,

Marc Bertolino, AIA, LEED AP