



Complex Child E-Magazine

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Epilepsy Three Years Later by Josh Bauman

July 9, 2008 started as any typical day in our house. I went to work and my wife Annette was going to take Jackson, then three, to see a movie. My mom came over to babysit Kade, then five months old. My desk phone at work rang, it was my home phone number. I answered the phone to hear my mom telling me something I did not expect to hear: "I think Kade just had a seizure."



At that moment Epilepsy entered our life and began changing our perspectives. We spent nearly an entire month on the 12th floor of St. Louis Children's Hospital trying to control his seizures. We were thrust into a world of tests, wires, drugs, and questions that did not have answers.

When we came home from the hospital I was afraid to go anywhere with or without Kade. I remember one night we went to a local restaurant, and I was worried about what would happen if Kade had a seizure while we were there. How would we explain it to people around us, what if we had to leave the restaurant in a hurry if the seizure did not stop? All valid concerns, but as time passed, and we learned how to manage Kade's

seizures, the concerns have diminished, but not disappeared. For about a year after Kade started having seizures we watched him 24/7 for seizure activity. We even installed a video monitor in his room so we could watch him while he slept. The only problem was while we watched him sleep, we didn't sleep.

Three years later our son still has daily seizures, some days fewer than others. We have a small pharmacy on our kitchen counter: Keppra, Topamax and Klonopin, to name a few. We know more about Epilepsy than most new medical residents.

Jackson is now five and starting school this fall. Kade is three, has had more diagnostic tests than the average adult, and his blood (for genetic testing) has been in more states and countries than I care to count. We are on a first name basis with a large number of nurses, doctors, and therapists. At first we wanted a diagnosis to know what disease or condition we are dealing with. Kade has had over 20 genetic tests, MRIs and EEGs, and now it no longer matters to us. A diagnosis does not define a child.

The only thing we know for sure is that we are not letting Epilepsy run our life.

Having a child who is medically complex changes your perspective. Before Kade entered my life, I never took a second look at odd movements or repetitive actions children made. Now when I see a commercial with an infant and she jerks or does a repetitive action, the first thing that comes to mind is SEIZURE.

When Jackson was an infant we read all the books about what to expect and waited for him to reach milestones to make sure he was developing typically. Since Kade was born, we have thrown all milestones out the window and we are letting him define when and what he wants to do. We don't take for granted each smile, laugh or happy sound he makes. We know that life is very fragile, and to make the most of it.

Finally, here is an example of a humorous perspective change. When Kade was born I convinced my wife we needed a minivan. She reluctantly agreed saying she was too young to drive one. Since Kade rides in a wheelchair, now we are DROOLING over getting a wheelchair accessible minivan. It is funny how perspectives can change.

Josh Bauman is married to Annette, and they have two wonderful boys, Jackson and Kade. Kade started having seizures at five months of age and has since been diagnosed with Epilepsy, CVI, Global Developmental Delays, Development Encephalopathy, and a suspected Mitochondrial Disease. Josh and Annette also chronicle their journey at www.ourfamilyof4.com