Family introduction: I am Micaela Widman, mother of six children, four boys and two girls, in that order. Kai is 21, Jace is 19, Kale is 17, Sterling is 15, Brielle is 13, and Brenna is 9. My husband, Jerad Widman, is a medical doctor, in both family practice and ER medicine. We live in Overland Park.

Kai's Story

When Kai was a baby, he was seemingly super-healthy, but at age 1, things started to get challenging. He *never* followed directions, and responded to *no* discipline. He threw excessive tantrums (much more than a normal toddler), and didn't seem to be bonded to me at all. As he grew older, long story short, we found that he was extremely strong-willed and also extremely intelligent, which was sometimes a scary combination. The arguing and difficult behavior were exhausting, but we thought he was just a strong-willed child. We did our best to take the reigns on him and help navigate him. We loved him so much. In many ways, we adored him, as he was engaging, fascinating, and loved learning, but in other ways, we wished for a break.

Then, in December of 2011, at age 12 ½, life for Kai took a sudden and devastating turn. He began having dark thoughts, as in he didn't want to live anymore. He assured us he didn't actually want to hurt himself, but he didn't want to live, either. He also started freaking out excessively about everything, such as his brother sitting too close to him on the couch, or a small, easy homework assignment. His behavior, irrationality, darkness, and anxiety suddenly became a great concern. We took him to our family doctor, who did testing and couldn't find anything wrong with him. My husband also ran as many blood tests as he could think of, and nothing showed up. My husband specializes in helping people with mental illness, so he decided to try Kai on some Zoloft. At first, it seemed to help, and his behavior even got better. But after a few weeks, the behavior problems and all of the symptoms came back, and things started spiraling downhill.

We spent a few months trying to find the right medication, but by fall of 2012, we needed help. Pure craziness had come upon Kai, and he had also become suicidal. We entered him into a psychiatric hospital where he drove the staff so nuts, they actually called *me* for advice. They put him on six psychiatric medications. Very briefly, things were slightly better, but over the next several months, they got *way worse*, and Kai was asked to not come back to school (he was placed on home bound studies). We found a seasoned psychiatrist, and we continued to go with the psychiatry route for several more months (a year and a half total for psych). The mental illness symptoms only continued to increase, however, and we became concerned that this increase might actually be from the medications. We wanted to take him off the meds, but we were scared to! We didn't know what might happen, if life would be better or worse without them.

In 2013, things became even more grave, as Kai started having full-blown, severe, and serious physical symptoms, which correlated in time and intensity with the mental episodes. We couldn't find an explanation of the connection between the physical and mental symptoms, and then his psychiatrist told us the physical symptoms "didn't matter." She suggested that he be institutionalized. We couldn't take it anymore, including taking the fact that Kai's physical symptoms were being dismissed. We decided to look into "alternative medicine," since we had given the traditional doctors over a year and a half. Things had changed so fast that by the time we started looking at this as a physical illness, the list of symptoms was a mile long.

Mental symptoms: Kai was loud, disruptive, made strange and repeated noises, wouldn't respond to requests or follow directions, was delusional (examples: thinking he was someone else or thinking he was on a reality show), spoke in different accents incessantly (unable to stop), was uncooperative (no matter how urgent or important something was), was micromanaging to his siblings and us, picked fights for *hours at a time*, had no boundaries with regard to space, was combative, provocative, and harassing. He would accuse, target, and scream at people for long periods of time, emotionally driving them to the ground. Anyone who tried not to engage with him would only end up having him follow them around and around, demanding loudly that they argue with him. His arguing was fierce and relentless. He was 100% irrational and manipulative, often explosive, and he couldn't empathize at all. He was verbally aggressive, belligerent, and hostile. Sometimes he was the opposite, too: giddy, silly, bizarre. He had rages that were so powerful and out of control that we sometimes had to pin him down. His adrenaline was so off the charts that it would often take four of us to do this. (Even then, he could still escape us sometimes.) When the rages were over, he would shake uncontrollably from the stress hormones wearing off. He would be pale and have no muscle tone. He would sometimes apologize to us and thank us for helping him through the rage. We spent an average of 20 hours per week dealing with full-blown rages, and many other hours dealing with the other symptoms. He became extremely suicidal. He tried or "tried" to kill himself over 250 times over 4-5 years, and we had to take all recommended measures to keep him safe. The police and EMS knew him by name, because we had to call them so much. (They were wonderful, caring, understanding, thankfully.) As things worsened, Kai became non-functioning. He sometimes babbled things that didn't make sense, having impaired judgment. He often had a "far off" look on his face. Occasionally, he had panic attacks. His words, actions, *his eyes*, everything, showed craziness, or his "not being there." Many times, he couldn't bathe, brush his teeth, trim his nails, tie his shoes, clean up his room, or even eat. He became my full-time job. He was extremely depressed and isolated, wanting no more relationships. In rare moments when he could actually relate to us relatively normally (again, relatively), he would explain to us what was going on during the episodes and mental blocks. He said his thoughts were torturous, and he didn't want to be that way. He said he HAD to argue with us or he would become physically ill. (That is how I knew the arguing had to be a manifestation of OCD.) He said that he didn't process behaviors until after the fact. He said he "wasn't driving the car," meaning he wasn't in control of anything he did, and said he wished to be out of the body he had no control over.

Physical symptoms (which again, happened simultaneously to the mental ones): dilated pupils, failure for pupils to react to light changes, "far-away" looks, eyes looking like a wild animal's eyes, extreme pallor/ashen color to his face, lethargy, a sort-of neurological paralysis that could last up to 90 minutes, convulsions, periods of time in which he had super-human strength. He would have moments in which he became cataplectic, or at the least, had poor muscle tone. Sometimes, he would have complete body collapse. His face would swell a little bit sometimes, and he would get a reddish-purplish color under his eyes. He started to have mild, seizure-like symptoms (dazed and glazed expression, unable to move, speak, respond, blink much, or even swallow). He had severe blood pressure drops, very frequent and dangerous blood sugar swings, dizziness, and shakiness. He was incredibly reactive to his own glucose rises (though he had a 24-48 hour delay of symptoms after eating sugar). Sometimes, his heart would beat extremely fast and hard, like it was trying to pound out of his chest. His resting heart rate was sometimes not steady. He often had a general and terrible feeling of sickliness, for lack of better description. He swung from totally hyped up with outrageous energy to totally depleted, like a wet noodle. When hyped up, he had the mental symptoms. When depleted, his reflexes would be slow and his speech would slur. He had different kinds of sleep issues. Sometimes, he would have terrible insomnia, and other times, he would sleep up to 17 hours. He would wake up not rested, but still completely exhausted, even when he had had a lot of sleep. His circadian rhythm changed to a 27-hour cycle, rather than 24-hour. He started getting frighteningly skinny, and his body seemed to be shriveling up at times. Strangely, this seemed to happen more in the winter, and he would get somewhat better in the summer. We were finally told by doctors that his body couldn't process nutrients, including fat and protein, but no one knew why or what to do about it. He also had "hunger unawareness," and would often desire to not eat, even when he had low blood sugar and needed to eat very badly. I made him eat anyway, even if I had to spoon the food into his mouth.

In addition to the trigger of his own glucose rises, his other triggers included: random other foods, hunger, a vestibular dysfunction we had to have worked on, lack of sleep or poor sleep, fumes, stress of any kind, growth spurts, lack of sunlight, standing up from either sitting or lying down, noise, vitamin B, winter, barometric pressure changes, and oftentimes any sort of work (as he had an inability to motor plan). Sometimes he was set off when there was no external trigger. We knew something unknown was going on internally at those times.

Then, in August of 2014 (I think), due to a misunderstanding with his doctor, Kai consumed some honey. Over the next few days, his mental and physical symptoms became so out of control that Kai's health entered into an emergency situation. We had to go out of our comfort zone and take him to the hospital. He was admitted for three days. Thankfully, all but one of our doctors acknowledged the physical nature of his illness, but they were completely baffled as to what could be wrong with him. At one point, Kai became unresponsive, his pupils dilated and his eyes fixated on the ceiling. The rapid response team was called in. They ran several tests on him, which required poking him with a needle. Kai didn't move, didn't even blink, when they poked him. All of his tests during that episode came back negative. No matter how many doctors he saw or how much testing we did, nothing at all showed up! Our son was so ill – seemingly deathly ill at times – but no one could figure out what was wrong with him. By the time we left the hospital, still with no answers, the course of the honey-induced episodes was winding down, but it would still be several more days before he made it back to his baseline.

Making Kai's very long story short, we went through many more doctors and health offices over the next several years, most of whom didn't take insurance. We were grateful for them, though. We spent several years and *tremendous money* to finally (and thankfully) get Kai diagnosed with and treated for dysautonomia (dysregulation of the autonomic nervous system) with many manifestations (two of them were POTS [Postural Orthostatic Tachycardia Syndrome] and Adrenergic Postprandial Syndrome), plus seasonal affective disorder (SAD), and **Autoimmune Encephalomyelitis (his case could be described as PANDAS Plus, a very severe case)**. A test called the Cunningham panel came back so high (4/5 areas of the brain that were under antibody attack) that the lab called our doctor out of concern. We used KU Integrative Medicine, functional neurology, Brain Balance Centers, physical therapy, chiropractic care, acupuncture, biofeedback, GAPS diet, tons of nutritional supplements, light therapy, Plasticity Brain Centers in Florida, and got him a tonsillectomy, all before finding out about **IVIG and plasmapheresis**. He had those, too, at the University of Missouri, Columbia, his senior year of high school, under the care of Dr. Michael Cooperstock.

When we met Dr. Cooperstock, everything changed. Having answers meant everything to us. Having a medical doctor who acknowledged, understood, and validated Kai's symptoms was a game changer. Having a doctor who understood at least part of what was wrong with our son, and especially having a doctor who knew *how to treat the illness* was life-giving. And finally, having a doctor who had trained other doctors and staff in the hospital to know how to care for patients with neuro-immune illnesses was like finally breathing fresh air. Kai's story didn't end there. We were able to find out more answers and ways to treat his body, but in the end, Dr. Cooperstock helped save Kai's life.

Kai is now a junior at KU. He is studying computer sciences, and has a 4.0. He was able to graduate from Blue Valley North with a 3.95. He was on the dive team at BVN, and is now on the disc golf team at KU. He has been employed, has completed a college internship, and will be interning with Garmin this summer. He has energy, and he has friends for the first time in many years. Best of all, he has only minor and residual symptoms, and he feels very good.

Education for doctors for illnesses of brain inflammation, early diagnosis, and a wide range of treatment options is vital for kids like our son. There was a night and day difference in the knowledge of the Kansas City hospital and the University of Missouri hospital that we went to. That knowledge made all the difference.

Brielle's Story

In March of 2017, our lives were again forever changed. Our daughter, Brielle, who was nine, and was neuro-typical, was on her third winter illness in about a three-week period (it was a terrible winter for illness that year in Kansas). A few days into the third sickness, on March 7th, I noticed a little episode in which Brielle's eyes rolled into the back of her head. It was scary looking. That evening, it happened again, in front of my husband, and I got him to see it before it was over. I said, "What was that?" He answered, "I have no idea. I've never seen or heard of anything like that before." I told him I was worried there was something wrong with her brain. He nodded, but told me we should just keep watch over her because if we took her to the ER, the chances that she would have an episode there were slim, and the chances that they would know what was wrong were zero.

The next day, she had about 4-5 of these episodes, but though she was pale and lethargic, she was fine, neurologically, in between them, so we just continued to keep watch. The morning of March 9th, though, she was going in and out of consciousness, and the eye-rolling episodes were happening about two per minute. I took her to the ER right away. When I lifted her off the couch, her body was as stiff as a board. At the hospital, after regaining consciousness, she had difficulty walking, due to stiff legs. The hospital kept her for three days, but just as my husband had predicted, they had "no idea" (their words) what was wrong with her, neurologically. They said she had just had the flu, gave her some meds and fluids, and sent her home.

Over the next few days, things went downhill. I realized that each eye-rolling episode was actually the tail end of a long spasm that was starting at her diaphragm and rolling up through her chest, into her throat (larynx), and out through her eye muscles. These spasms became stronger, more rapid, and more frequent. We took her to a functional neurology chiropractor that we greatly trusted, but unfortunately, he was unable to do anything to bring her relief.

March 16th, the spasms became so violent that her larynx was closing up her airway, and her whole body was going into convulsions. She was only able to breathe a few times per minute with these spasms. They were torturous. We rushed her to the ER and she was admitted again. She stayed in the hospital for 24 hours, but they still were not able to offer suggestions as to what was wrong with her, nor what to do about the spasms.

Within the next week, Brielle's spams became even more out of control, throwing her body all around and continuing to make breathing difficult. Each day, she was plagued by these overpowering, strangling spasm patterns for several hours. **We were at a loss because by this point, so many doctors had looked at her, saying there was nothing medically wrong with her. We later got her in to see an ENT, who confirmed she was having diaphragm spasms and laryngospasms, but he could not tell us why.**

Adding to the confusion, her left foot started turning in while walking. A couple of days later, she started losing consciousness again and began collapsing onto the floor. My husband had had enough of the pediatric doctors in the Kansas City area. He made some phone calls, got a recommendation, swept Brielle up, and took her to a hospital in Wichita.

Over the next ten days, we found that our nightmare had just begun. The episodes of spasms turned into seizures, and she had 300-500 of these seizure cycles per day. She was unable to breathe during two portions of each seizure cycle, but would make up for it with enormous breaths, as her body learned to accommodate. She had tachycardia, crazy and completely unnatural eye movements, neck extensions/spasms, hallucinations, and periodic stiffness in her toes, feet, legs, and hands. She had losses of both voluntary and involuntary muscle movements, and lost her abilities to walk, speak, process auditorily and visually (most moments during the day). In the short and few moments where she could see and hear, she didn't recognize us anymore. She screamed blood-curdling screams hundreds of times per day as a part of her strange seizure cycles. The doctors believed she might have autoimmune encephalitis, so they gave her 5 days of IVIG. The third day of IVIG, she stopped declining and entered her new, terrible baseline (but at least it was a baseline). Unfortunately, the doctors were not able to diagnose her. They sent us home with a feeding tube and machine.

After a total of eight hospitalizations in nine weeks (at five different hospitals), lots of testing, lots of doctors, and thousands of miles on our car, Brielle was finally diagnosed with anti-GAD65 autoimmune encephalomyelitis at the University of Missouri, Columbia, and later, Stiff Person Syndrome (SPS) by a neurologist in Seattle. Anti-GAD65 antibodies are antibodies that the immune system is not supposed to make at all. They attach to GAD65 enzymes in the brain, causing the body to not be able to produce the calming neurotransmitter GABA. This causes the SPS. The encephalitis was just an additional "gift" of the antibodies. We also found elevated levels of ASO (strep) antibodies and mycoplasma (walking pneumonia) antibodies. A Cunningham Panel we did in April came back 5/5 – in the top 3% of worst encephalitis cases.

Going back a bit, by the end of the second hospital visit, Brielle's brain had been wiped out from the brain injury caused by her immune system. Our once happy, joyful, talented, loving, smart, friendly daughter had been reduced to nothing other than a bed-ridden body with no consciousness and no movement control. After a few weeks, she started showing signs of development again, but the development was as an infant. She went through months of baby and early childhood development: reaching, rolling, crawling, and eventually walking on her knees. She cooed, babbled, and weeks later, learned to indicate "Yes," by blinking and "No," by looking up. As she became mobile, she put everything in her mouth, took everything out of cupboards, went through the terrible twos again, played "peek-a-boo," and watched baby TV shows.

She had very little stability, as her excitatory neurotransmitters were constantly being set off like fireworks. She often lost consciousness, bolted outdoors, became violent, screamed, made crazy noises, continued to have seizures, became stiff all the time, had little muscle control, and had continued spasms, etc. She lost control of her bladder and had to start wearing diapers again. I couldn't do any of my normal mom duties because I constantly had to make sure she wouldn't hurt herself, hurt someone else, or escape. The worst thing of all was that we missed our real daughter so much. We hadn't "seen" her since the beginning of April, and our hearts ached so badly for her to be back. We didn't know if that would ever happen.

Over the next 16 months or so, were able to get her 3 rounds of plasmapheresis, more IVIG, and a round of Rituximab. These greatly helped. She was only able to go to school a couple of hours a day, at the most. She worked with excellent professionals at school for her special needs. When the school tested her academically, she was at or below kindergarten level (though at the time, she should have been a 4th grader). Before her illness, she scored high and did excellently in school. She now had tremendous instabilities throughout each day, and she had a number of different kinds of seizures each day. She used a wheelchair because she could only walk on her knees, and she still had to have a feeding tube. But she was better. She was conscious, had risen above infant stage, and could communicate with us in her own way, among other things.

Just as with my son, Kai, the story continues in that we were able to find immunomodulating treatments and supplements that were tremendous help. We found physical therapists and an occupational therapist who all did great work, and our functional neurology chiropractor helped a lot, too. It took a big team to bring Brielle back to us, but **we could have never brought her back to us without the diagnoses and treatments that we received at the University of Missouri and through our doctor in Seattle, who partnered with another local hospital to give Brielle her last (4th) round of plasmapheresis. Our U of M doctor is retired now, so we have to fly Brielle to Seattle once a year to see her neurologist there, as she now oversees her total care.**

Early diagnosis and early treatments are imperative to beating these illnesses. Just like with cancer and other conditions, time is of the essence when combating them. Having education for Kansas doctors and requirements for insurance companies to pay for the tremendously expensive treatments would be extremely beneficial for patients and the families suffering from these neuro immune illnesses.

Thank you for reading our story.