

Good morning, Chairman Longbine and members of the Senate Insurance Committee, I am Brielle Widman, from Overland Park, and I am 14 years old, in the 8<sup>th</sup> grade. What I will be sharing with you today is only a tiny part of my story, and it also happens to be the part of my story that I don't remember, as there are about six months of which I have no memories. So, what I am sharing with you today, I only know by the testimony of my family, doctors, and others.

Five years ago yesterday, actually, on March 9, 2017, when I was 9 ½ years old, my mom came downstairs in the morning to find me lying on the couch, going in and out of consciousness, and having repeated, long spasms that started at my diaphragm, rolling up through my larynx and out through my eyes, causing my eyes to roll into the back of my head. When she lifted me up to rush me to the hospital, she found that my entire body was as stiff as a board. She said that lifting me was like lifting a two-by-four. At the hospital, I was admitted, but the doctors couldn't figure out what was wrong with me.

I went downhill fast. First, the spasms became stronger, intermittently cutting off my airway and causing my oxygen levels to go down. My left foot started turning in when I walked. I started having horrible, full-body, involuntary, convulsion-like movements. I began losing consciousness again for short times, and then, I started collapsing while walking.

By April 3<sup>rd</sup>, I was having **300-500 seizure cycles per day**, every day, unable to breathe much of the time during the cycles. I had a rapid heart rate (as high as 180 beats per minute), crazy and completely unnatural eye movements, hallucinations, neck extensions and spasms, and other spasms. I lost both voluntary and involuntary muscle abilities, and this was just the beginning.

I even lost my abilities to walk, speak, eat, see, hear, and connect with the world in any way. In the short and few moments in which I could see and hear, I didn't recognize my parents anymore. I screamed blood-curdling screams at the sight of them or any human face. I lost all cognitive brain function, and I was completely unaware of the world I was in at *all* times. My parents said that my eyes were far away, and even if something stimulating happened to me, like a bit of cold water accidentally falling on my feet, I had no reaction to it at all. My body couldn't sleep, either. One night at the hospital, they gave me Valium, Propofol, and Benadryl, all by IV, to try to allow my body to rest, as I continued with the seizure cycles, but the meds didn't work. They finally gave me more Valium and I went down.

Within 25 days of my first symptoms, I had lost everything about me except for my vital organ functions, and my parents knew those functions were next to go if something wasn't found to stop my swift decline. I was now just a bed-ridden body of working internal organs, unable to stop moving and seizing, with a non-working brain and non-working muscular system. I was on my third hospitalization at this time, and the doctor there suspected that I had autoimmune encephalitis. He ordered IVIG to be given to me daily over 5 days.

On the third day of IVIG, for the first time since it all had begun 27 days before, my condition stopped declining. Although I wasn't yet regaining any function, IVIG was giving my body the tools it needed in to begin to battle for the first time. For the first day since onset, I was no longer spiraling downhill. I was able to establish a new baseline. It was a terrible baseline, but at least my state was more stable. I was later officially diagnosed with autoimmune encephalomyelitis and Stiff Person Syndrome by separate specialists at the University of Missouri and in Seattle. After three years of intense treatments and therapies, I made it to remission.

Again, that is just the tip-top beginning of my story, but it is the part that is relevant for today and for what I can share in the time I have been allotted. The IVIG I was initially given saved my life. My older brother also has a diagnosis of autoimmune encephalomyelitis, and he, too, has had IVIG. My brother was deeply suicidal for years due to brain inflammation, and IVIG was critical for him on his road to recovery.

Thank you for hearing my story. Because of the life-saving power of IVIG, I am able to stand here before you today. My family and I respectfully ask that you vote for Senate Bill 2110 to save Kansas kids. Thank you.