

Dear Chairman Longbine and Members of the Insurance Committee,

Thank you for your service to the State of Kansas. I am writing to you in support of HB 2110, the PANS/PANDAS Insurance coverage which was passed by the House. My family and others have been negatively impacted by this disease and the lack of insurance coverage for treatment.

Hi, my name is Aria Brent. I am 11 years old and I have PANS.

In June 2019, my life changed overnight. I had ticks where I would do strange robotic looking movements, and I was really depressed. I had a lot of raging moments and severe OCD. I couldn't wear clothes and I was terrified of germs. I couldn't sleep - I often stayed awake all night. I hallucinated that there was someone in my room or someone out to get me, so to feel safe I would hide knives in my bed. During that time, my mom told me that she was scared to wake up everyday because she didn't know how bad I would flare up. She said she hated seeing me hurting like that. My extended family was also very concerned for me. Relationships with neighbors, family, and friends got very hard because I couldn't be outside for more than 5 min. My mom always asked why I was going inside so soon and my reply was I didn't feel good. I couldn't go to school or do school work for two months because I got so sick.

My mom took me to the doctor, but she didn't know what was wrong with me. Next, she took me to a counselor but that didn't help. I started going to occupational therapy, too. My mom started researching and trying to figure out what was going on with my body and what could help me get better. She learned about PANS and called the doctor right away. The doctor said she had hardly even heard of PANS so my mom sent her information about it. Our family doctor agreed with my mom that it could be PANS. We started to run tests to see if we could find out why I had this. She put me on antibiotics to see if they would help. The antibiotics reduced my symptoms enough that I could manage going to school again, but I was still quite sick. My mom took me to Children's Mercy, but they could not help. Finally, after four months of being so sick and no doctors able to help, my mom found a naturopath that helped us start to figure out why I was so sick and what we could do to help me get better.

My parents have done everything possible to help me get better, but it has cost them so much money and I still struggle with some PANS symptoms, even after lots of treatment. There are not any doctors in Kansas that really know about how to treat PANS kids. It is really important to educate doctors about this syndrome so other kids like me can get treated quickly and effectively. It's also important for insurance to help with the treatments because they can be really expensive and hard on families. Thank you for listening to my PANS story. Passing HB 2110 would help tons of kids like me.

Thank you,  
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