

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 across the state have been negatively impacted by this disease and the lack of insurance coverage for treatment. This had been a long long road. Since I have two children that are majorly affected by this, I'm writing two letters. As I write, I am in tears thinking about all of the potential happiness my boys have lost. It has been a non-stop struggle, feeling like we are alone in helping our children and looking for answers. We have seen so many doctors. Most were out of pocket for testing that was not covered by insurance. I have no doubt that my children will not be able to work if I cannot get them completely healthy again.

It has been 1.5 years since I realized our pediatrician practice and Psychiatrist would NEVER be able to help my boys, or even try to help my boys. I know the oath is "do no harm", but the inaction has definitely caused harm. I am not a doctor, but I have spent so much time reading medical journals looking for help. From about age 7, my oldest son has had problems. He is now 19 and a freshman in college. He was cute, and very smart. Sometimes I would notice what seemed like a switch flipping in his brain and he acted like a different kid entirely. He would say the weirdest most hurtful things and would throw fits. He seemed possessed. Imagine a year old telling you that he wishes you weren't his mom. Imagine him saying I wish you were dead. I know now that he said these things because inflammation in his brain was hurting him. We had to take things out of his room to keep him safe. He also had various skin rashes off and on. Getting those diagnosed was much more difficult than it should have been. We saw the pediatrician, and multiple dermatologists, waiting forever each time for an appointment. I did not realize that the pediatrician and dermatologist were both wrong when they diagnosed yeast. The inadequate answer was always "let's wait and see". At one point my son was diagnosed with rectal strep. I found this information on my own on the internet after nothing from the doctors helped. Yes, Dr. Google. The pediatrician was very skeptical when I mentioned it. She did a culture anyway and it was positive. He was put on 10 days of antibiotics. The behavior problems still continued. I reached out to the pediatrician and the school counselor time and time again. Neither offered anything that helped. My son was accepted into the gifted program at his school. We got a referral from the pediatrician and my son started seeing a psychiatrist at age 9 since he could not pay attention or think straight. The psychiatrist diagnosed him with Adhd and prescribed medicine. He did not have the hyperactivity portion of adhd, only the attention deficit. My son very reluctantly played basketball and soccer. He constantly complained of foot pain and knee pain. We took him back to the pediatrician. She said it was growing pains and he was fine. I took him to a podiatrist anyway, since my son was in serious pain and it needed to stop. He wore knee braces, and orthotics. He was still miserable and even though he was taking adhd and pain medication. He became depressed. He quit sports completely. All through this he was still seeing the psychiatrist. We went back to the psychiatrist and she put him on an SSRI. He gained 40 lb in 2 months. I did not realize that ssris can do this. They make it possible for the body to just store the food as fat rather than using it as fuel. He was not eating more food than before. We trusted that the psychiatrist knew the right path since she is an MD. He continued to struggle with psych meds that didn't really help.

Looking back, I didn't know at the time that all of this was related. Attempting to figure out what is wrong with my child and why they aren't like other children.

Getting treatment has been extremely difficult, and I have been learning along the way, attempting to get our regular pediatrician doctors and psychiatrist to hear me. I do not even remember how I came across PANS and PANDAS, but it was through various google searches. We went to a Lyme disease clinic for help that I also found on the internet. It was very expensive since only some of the testing is allowed through insurance. Once my son was diagnosed with PANDAS, we went back to the pediatrician. She said how "rare" this autoimmune inflammation is. I have since found that it is not actually rare, it's just not properly diagnosed and kids are suffering. It is certainly not rare in my house. We started seeing another doctor for his pain, this time a Rheumatologist. She has since diagnosed him with psoriatic arthritis. He recently started on a very expensive injectable medication that isn't helping yet. I have no doubt that he would have preferred to fix this as a 7 year old rather than miss out on his entire childhood being sad and in pain. Though he is still smart, he continues to be in pain and isn't thriving at school. He cannot concentrate. He sits in his room and doesn't attend class. He scored a 35 on the ACT and cannot make himself go to classes. I would be mad if he had any control over this. He just sleeps.

My older brother also has been majorly affected by autoimmune encephalitis. He has been evaluated in the past for autism. While they said he does not have autism, personal relationships are almost impossible for him, and he works third shift at a bakery. He does not make enough money to sustain on his own. They cut his hours sometimes and he cannot effectively speak up for himself. My 85 year old father has been helping him by supplementing rent money but he can no longer afford to do so. He will need public assistance. He did not qualify for disability services in the past because he was considered borderline. This situation could have been prevented with a proper diagnosis as a child.

Inflammation is very bad, especially in the brain. We have struggled finding doctors to help. We have good insurance but have been unable to use it. We have spent thousands of dollars trying to find treatment. Illinois passed this legislation in 2017. Please let Kansas be next and help these children afford to get help. That in turn will encourage pediatricians to read the documentation regarding PANS/PANDAS actually treat it instead of saying nothing is wrong. My children are damaged from extended inflammation and it should not have happened.

Early diagnosis and treatment is essential to healing the sufferers and for restoring their abilities to be healthy, productive members of society. Please support this important legislation as it works its way through the Senate chamber. I can be reached at 913 608-6912 should you have questions or require additional information.

Thank you very much for your consideration.

Patricia Lanter

10559 S. Millstone Dr.

Olathe, KS 66061

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 across the state have been negatively impacted by this disease and the lack of insurance coverage for treatment. This has been a long long road. This letter is in regards to my middle son. I have also submitted a letter regarding my oldest child. My poor boy has gone through so much. There were so many clues, but since I am not a doctor, I did not put them together. I also believed our pediatrician and psychiatrist when they said his behaviors were normal. As a toddler my son would scream and cry for hours over seemingly tiny problems. He never had any fevers or colds that I can remember. He did have some rashes and also wet the bed until he was about 9 years old. I remember my son "waking up" from a dead sleep in the night when he was about 4, screaming over and over "I want my mom". I was holding him as he screamed and flailed. He has extreme social anxiety and began to have OCD about two years ago. He would collect bits of metal and get very upset if he couldn't find it. He was also pulling out his hair. We always saw that he was so very smart, but many days he cannot put his thoughts together. Homework takes hours and is a hands-on activity to keep him on task. After I came across PANDAS, I mentioned it to the pediatrician. She discarded it as a possible diagnosis. I found a practitioner to help. I was not sure what to expect from the test results. I was shocked when they showed evidence of a strep infection. I did not know that he had strep. Since that diagnosis, he has seen several alternative practitioners as well as a rheumatologist. He has been diagnosed with psoriatic arthritis, an autoimmune condition, likely from the long term inflammation. Additionally, the tests also showed positive ANA- antinuclear antibodies. His own body has produced antibodies to the nucleus of his cells. He is being watched for lupus and other conditions. We are so devastated for him that this could have been prevented. He is very upset that he has such severe social anxiety and psych meds do not help. He does not have friends and cannot speak when around peers. He was kicked off the robotics team in middle school because he couldn't talk. He did try to get into the 21st century program for engineering in the Olathe Public Schools, but his interview did not go well. He was very disappointed and does not have the confidence to try again. We have been to many doctors over the past 13 of his 15 years. The latest was a naturopath that spent 4 hours with us. He is doing somewhat better since seeing that doctor, but \$1800 was a lot of money to spend without any help from insurance. His childhood has disappeared and he did not have any fun.

Early diagnosis and treatment is essential to healing the sufferers and for restoring their abilities to be healthy, productive members of society. Please support this important legislation as it works its way through the Senate chamber. I can be reached at 913 608-6912 should you have questions or require additional information.

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