

March 10, 2022

Dear Mr. Chairman and Members of the Senate Insurance Committee,

I am a mother to a young 9 year old child who was just newly diagnosed with PANS by a pediatrician who has treated many PANS/PANDAS patients. My son began with symptoms in September after a viral infection. After a break, he started back up with symptoms in November. Some of the symptoms he has experienced have included hallucinations, feeling of dying, paranoid ideas that people are watching him, huge pupils, inability to focus in school, vocal tics, facial grimace, sleep issues, fear of the dark, fear of loud sounds, separation anxiety, body aches, irritable, obsessions with electronic games and building blocks, confusion, loss of skills in school, and regression. Much of the day he is genuinely a sweet boy, but these episodes come unpredictably. We were not able to get in to see our family doctor for 3 weeks after our first phone call November 18th. We weren't scheduled to see a neurologist until 8 weeks after the November 17<sup>th</sup> onset of symptoms. And that was just supposed to be a consult with an MRI to be scheduled later if necessary. Meanwhile, our family was turned upside down watching our child suffer with these episodes and thoughts. The only treatment ideas came to us because someone we knew had posted about their child having a sudden onset of extreme symptoms, and I asked this parent what they did. We were told to start with ibuprofen, and that we needed to try to get steroids to begin with if our doctor would do it. We then realized an awful truth, it's very hard to get a doctor to listen to you about this issue if you live in Kansas, and it's also hard to get proper prompt treatment. Our family doctor could only do so much, he was not really sure what was going on with our son. And the wait for the neurologist seemed to be a lifetime away. Meanwhile, we spent nights with our son on a mattress in the living room and a parent on the couch because he was afraid to sleep alone, and also because we were unsure how safe he was on his own. Things escalated when our son began to go catatonic or to pass out. We ended up in the ER in mid-December, but they opted to do no tests stating that the neurologist's appointment in 3 weeks would glean more than their testing. This pushed us to get in to see the neurologist right away. Sadly, we walked away from that appointment with directions to give our son vitamin B2, and put him on a good sleep schedule. It was mentioned that this could be behavioral, sleep deprivation, or migraines. Our son had no headaches at that time, no history before this of neurological issues, and no family history of such. There was no real help offered, even with the report of hallucinations and thoughts of dying. We were essentially left on our own. Without any idea as to how soon we could get in to a doctor who would give us more help than this, we asked the family doctor for help and he did order steroids for a week. The hallucinations stopped after that treatment. Finally, something worked. But so many other symptoms remain including the thoughts of dying. We decided to see a doctor out of the state who has treated hundreds of PANDAS/PANS patients. Since seeing him, we've had many blood tests and much more support. We have been told how to treat the different issues, and have some improvement with our son actually going to bed at 8:15 and sleeping until morning most nights. He has had some weeks with very little tantrums or other episodes, but then they come roaring back for several days. It's exhausting, and extremely sad. Our doctor has suggested our son may need IVIG in the future. We will have to find a way to raise funds for this treatment if the doctor deems it necessary. We already are aware that our insurance considers

IVIG for PANS and PANDAS to be experimental or investigational, and therefore, they do not often cover it. We are a family with 8 children (4 are adults) , my 9 year old is our youngest child.

I have attached a few photos. The first is my son in July, playing for his hometown baseball team. The second is in December the day we ended up in the ER and were sent home. The third is a recent photo, he does not like pictures these days so he often looks away. His big sister often takes his hand, offering support. The hat is because his eyes have been more sensitive to light at times since his symptoms came in November.

Even though this bill as it stands today would not get insurance coverage guaranteed for my son this year, I want it to pass. I know the pain and suffering the families go through, and have watched the anguish on my son's face when he does not understand why his brain and body are a prisoner to this post infection syndrome. My hope is that some families would not have to wait for necessary treatment that can make a difference in their children's future. Better to get relief for every child possible as soon as possible!

Thank you for reading,

Dawn Lewis  
Gardner, Kansas

