

Dear Chairman Longbine and Members of the Insurance Committee

I would like to thank you for considering my testimony, and I am writing this in support of PANS/PANDAS insurance coverage.

My case starts when I was just four and a half when one day I had a sore throat, I was taken to the doctor's office to get a strep test thinking that I might have had strep throat, however, the test came back negative. It turned out that I had an A-Typical case of strep throat, this, left untreated led to my and my parent's life to change forever. I was suddenly labeled with ADHD, Autism, and behavioral issues that I had never had before. My parents took me to an occupational therapist, developmental pediatrician, and Psychologist but none of them could tell my parents what was wrong. I was a different kid, I had severe separation anxiety and anxiety in general, I no longer walked on flat feet but everywhere on my toes, speaking was difficult, and sometimes I could not think straight, I lost most of my motor skills.

As I grew older my parents took me to different doctors but still could find no answer, my issues grew as well, my grades suffered when I was in school, PANDAS affected my social skills, and I did not have the ability to grow up as a normal kid. Finally, at the age of eight, my parents found a doctor who had worked with victims of PANDAS before, and finally, my parents and I had an answer, after 4 years of suffering we found out I had PANS/PANDAS. My parents put so much money and time, and over the years I got so much better than I was before. I no longer had behavioral issues, my motor skills came back, and my anxiety got so much better than it was before.

Even though I was doing way better than I ever had there is one thing that every victim of PANDAS fears, a relapse. The anti-bodies spike and everything that you and your family have been working hard towards feels like it just all disappears. I still hate thinking of this time, it happened to me when I was 13-14 years old many years since I first started to get healthier, it happened all of a sudden when I was sitting in math class, and I got a suicidal thought. This shocked me, I had never thought about anything remotely like this, but all of a sudden, I got it when I was in math class. I could not help myself I cried right there in math class, and when I got home, I was embarrassed that I had ever had a thought like that because I knew I was a person who would never have thought that. Over the next month my brain shut down, and I felt hopeless, I was doing so well, and then a relapse came which made me feel like what my family and I had worked so hard for was gone. Whenever I think of this very dark time in my life It makes me fear for another relapse but always motivates me to understand that this illness is not me as a person but like a parasite to my life. I was lucky that my parents had the time, money, and resources to help me with my Pandas, and even though now that I am 16 and am so much better it still affects me in little ways and will probably for the rest of my life.

This is not just me however that had to suffer through this but countless other kids and families as well, some as lucky as me and some not so lucky. Some kids and families don't have the time, money, and resources like I did to help make them better, and they have to suffer through this on a day-to-day basis some may even know what they are having to deal with but just don't have the ways to treat this illness. You however could make it so that these families do have the resources to help their kids, that millions of kids could have a stable future and feel like themselves again, so kids can feel relieved and hopeful. You could change so many lives and give them so many opportunities. You could help!

Respectfully,

Meredith Bonge

memybg3@gmail.com

13931 W 71st Terrace, Shawnee, KS