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On Behalf Of:

Committee: Senate Committee On Health Care

Measure: SB628

My son (currently 10.5 years old) was diagnosed with PANDAS 4 years ago, unfortunately his symptoms started 6.5 years ago. It took us over 2 years to get him properly diagnosed. During this time, we saw physicians in 4 different cities and 3 different states. We were also told by multiple physicians he didn't have PANDAS, instead he had (ADHD, tics, OCD, separation anxiety, generalized anxiety, and insomnia) at 4 years old! How is it a child this young had all these diagnoses one day but didn't have a single symptom the days to years before? These symptoms occurred after another undiagnosed strep infection. We watched him for 2.5 years deteriorate, withdraw from the world and his family, and become a shell of the child he was. We lost our loving, energetic, eager to learn child to someone who wouldn't leave the house for fear of getting lost. Watching him suffer was the hardest thing I have ever done as a parent.

I am beyond grateful to our pediatrician who supported us in our search for a proper diagnosis. We are also currently being followed by the Children's Postinfectious Autoimmune Encephalopathy clinic in Tucson, Arizona and my son is thankfully doing well. We found physicians and nurses who have supported us to get the correct diagnosis and treatment. Because of this he can attend school, loves reading, writing, playing with his siblings, and Star Wars. Thank you for taking the time to read my testimony. I hope my story can help another family searching for a diagnosis or treatment.