

Submitter: Tonya Robertson
On Behalf Of:
Committee: Senate Committee On Health Care
Measure: SB628

Dear Chair Patterson and members of the Senate HC,

I am in full support of SB 628. My son fights everyday with PANS to live his life. He is constantly fighting a live virus that hinders his body, giving him inflammation in the brain and nervous system. We never know if he is going to sleep through the night. Back story, Talon my 8-year-old son has a rare genetic disorder called Phelan McDermid Syndrome that gives him a severe intellectual disability, Autism, and a long list of other symptoms. He also has Non-verbal Autism and with his PANS it makes everything hard to manage. His team of doctors are struggling to treat him and don't always agree with the same treat. Some of his treatment is not covered by insurance making it hard to get everything he needs. This bill would help bring the necessary awareness that this is a true disorder, and deserves to be cover by insurance, and supported by everyone.

Anyone who meets Talon knows that he struggles with PANS and it breaks their heart that we struggle to get treatment and coverage for this disorder. Imagine seeing your child's eyes cross from brain inflammation, have severe OCD ticks where he cannot do anything else but mess with the doors in our home, or not be able to sleep but a couple of hours a night with heavy medication. I cannot carry on like this for much longer without relief, and I know he can't either.

When you are voting on this bill please keep me and my son in mind and the hardships we face every minute of everyday.

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