

Greetings,

I want to thank Chair Representative Rachel Prusak, Co-Chair Representative Andrea Salinas, and Representative Cedric Hayden for allowing me to show my support for House Bill 2390.

I want to share with you my family's journey with PANDAS. My son Harlin had back-to-back strep infections when he was in first grade. He was just six-years-old. Before his strep infections, he was outgoing, fun, loved hugs, helped others, worked hard on his "big boy" homework, and participated in class activities. After his strep infections, and when I did not know what was happening to him, he began to change instantly. His teacher and I thought it was the stress of almost being in second grade. He cried as he was doing speed math when he used to love the subject. He started hitting his head against his desk. He no longer wanted to participate in school activities. He would obsess about people coming into our house and hurting us. His rage was uncontrollable. He started wetting the bed, walking with his arms up like a dinosaur and developed a loud, barking cough and a repetitive neck tic. The list goes on. I was at a loss as to what was happening to my son.

We went to the pediatrician, who referred us to the psychiatrist in the office. Even this mental health professional was not sure what was happening. He thought he was suffering from oppositional defiance disorder (ODD), but that did not make sense. He was a smart, healthy boy and seemed to be regressing quickly.

During second grade, it got even worse. He started to scare teachers and his peers with his behaviors. Some of the teachers who knew him from his pre-k class were taken aback by his behavior change. I met with them every day. We had a 504 plan put in place. We saw a child psychiatrist who put Harlin on psychiatric medications because his symptoms now included OCD, anxiety, Tourette's Syndrome, and depression. These psychiatric medications caused serotonin syndrome and almost killed him. He then had a gene-sight test, which determined he cannot have psychiatric medicines.

During this time, I still was not sure what was going on with him. I spent my nights, and most of my free time researching his symptoms. My mother happened to come across an article on PANDAS/PANS, and she sent it to me, believing Harlin had many of the symptoms. I read this article and then started researching PANDAS because I knew Harlin had strep right before his behaviors began to change. When I found an article that listed the symptoms attributed to PANDAS, I checked off every single one. I sat at my computer, hung my head, and began to sob. I knew that I found what was wrong with my son. I also knew that our fight was not over because the text also referenced that treatment and treatment cost was a barrier for most families. I did additional research and took it to my son's

pediatrician, who officially diagnosed him with PANDAS. Harlin is also legally disabled and is now in special-ed with an IEP.

Our medical journey has not ended there. It was just the beginning. I have paid out of pocket for hyperbaric chamber treatments, ozone treatment infusions, supplements, fought for labs, antibiotics, and steroid tapers. Harlin had his tonsils out in June 2020, and we were hoping this would stop his re-occurring strep infections. However, since November 2020, he has been in a flare, and I have yet to find the source. I was told to “wait it out” by his pediatrician. When I asked if we could look into IVIG, I was told, “no”.

Harlin is not getting better, he is getting more debilitated. I pay for health insurance for my family. I desperately want help for my son. I want him to be cured. He should not be another statistic. IVIG could save him. He does not have many options. Psychiatric medications will kill him, and PANDAS can be a losing battle as well. I would appreciate your consideration of this House Bill. My son’s life matters.

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