

Testimony: HB 488

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My daughter didn't want to come testify. She still doesn't want to talk about her illness because her OCD involves her being "perfect" and sharing about it makes her feel less than. She's 13, an 8<sup>th</sup> grader, and the strongest woman I know. She has been battling PANDAS, this demon of an illness, that in her presented as a mental illness. It started almost overnight with severe anxiety, OCD and rages. It began shortly after having a strep infection in 2017.

Her OCD was so bad that she struggled to get through her morning routine. We were lucky; she could go to school, even with her debilitating OCD and anxiety. Many kids with PANDAS have such severe OCD and separation anxiety that they are unable to attend school. Kaylin could. She even could hold it together all day, so no one would know she had PANDAS. However, within minutes of getting home from school, she would fall to the floor in a fit of physical and verbal tics that could last for hours.

It took us ten months of multiple doctors and numerous tests to get her diagnosed. In that time, her anxiety increased, and depression set in. Her physical tics evolved from flaying hands to hitting herself or ramming her head into the wall. In her flares, she would scream and cry that she "wanted to die" or "just kill me," or perhaps the worse that cuts to the core of a mother, "I don't want to live like this." At the time she was 11 years old.

She started antibiotics and Prozac. The antibiotic helped bring her back to about 85% baseline. The Prozac treating her depression gave her the strength to go to school and hold it all together. With the treatment, she improved. Until Spring 2018 and allergy season, when her body's autoimmune response to allergies triggered her PANDAS and her anxiety and OCD spiked again. Her doctor increased her antibiotic and Prozac doses. He recommended IVIG. Insurance denied it. After a few months of daily rages and fits, she evened out for a while on the medications. Not great, but we were learning to live with our new normal. Cognitive Behavior Therapy was helping all of us to cope, but we were just coping, not healing.

After two years with PANDAS, Kaylin took a turn for the worse. She had a slight head cold and it took her down both physically and emotionally. Her suicidal idealizations increased. Her OCD and tics with full blown self-harm increased. She was lost to us in her fits of rage as she screamed and wailed from the torment in her brain.

Her doctor again recommended IVIG. We scheduled the treatment. We requested insurance approval. We paid almost \$10,000 out of pocket for treatment from her college fund as we waited to hear from insurance (they ultimately denied the treatment). In summer 2019, she received IVIG.

Over the course of the next few months, we slowly saw our daughter re-emerge. Her episodes lessened from every day to every other day to several days to once a week to every other week. For the first few months, every episode she had she would be worried that she "failed" us because of the cost. As much as we tried to reassure her that the money didn't matter, she was worried she "failed" us. That we wasted our money.

She started 7<sup>th</sup> grade, middle school, in the fall of 2019. She began to embrace school again; earning As and Bs and building strong friendships. She's starting to dream again and look forward to the future, instead of just coping and getting through the day.

IVIG saved my daughter. Saved her from this horrible illness. Saved her from debilitating OCD and anxiety and mental illness. This remission from this demon lasted for one year. In the first week of August 2020, she developed tics – physical and verbal. They started out small, but within a week, she was ticking from sunup to sundown. Tics of this severity were not a part of her illness before, but we now know is often prevalent with PANDAS.

We started the process to fight insurance again in the hopes to get it covered this time. Regardless, we knew IVIG worked for Kaylin. We moved forward with her second round of high dose IVIG. Within days of the treatment, her tics were diminished, not as frequent. Now two months since her treatment, she still has tics throughout the day, but her anxiety and OCD has lessened. We know from before it took several months until she returned to baseline.

I wish she could share her story with you. One day, I am convinced, she will.