

Written Testimony Re:
HB-447

In September of 2018 we "lost" our then 5-year-old son, Caleb to a horrible condition that we have since learned is PANDAS / PANS. At that time, our tenderhearted, well-natured son began kicking, hitting, and screaming at us. He started flapping arms, sticking his fingers in his mouth and using constant baby talk. He became very oppositional and then began developing obsessive behavior and tics. In addition, he began urinating and defecating in strange places. His school performance plummeted and he lost the ability to complete basic kindergarten level work. This change happened suddenly, almost overnight and has since affected not only him, but the entire family.

Over the course of 6 months (from September to February) we took him to see several doctors, and it was at the end of February when our General Practitioner said she thought he had PANDAS / PANS and sent us to a functional medicine psychiatrist for help. We saw the specialist in early March 2019 and we have been continuing his treatment of multiple antibiotics, LDN and additional supplements since that time. We also saw a pediatric neurologist as a second opinion, ensuring that we are taking the appropriate steps to "get our son back." All our treatment to this date and our appointments have been out of pocket and have not been covered by our insurance. We have continued treatment now for 18 months. All of our doctors visits have been out of pocket, not covered by insurance.

We have not at this time started the approval process for IVIG as we were told by our doctor that our son most likely wouldn't qualify as it is very difficult to get it approved. As a parent we would do anything within our power to heal our children and to know that there is healing available through IVIG, but that it is not covered by insurance is heartbreaking. Our family has not only spent our savings but also borrowed money in order to pay for treatment. In addition, I was forced to resign my position (our second income) and homeschool our children due to the severity of our sons symptoms.

Thank you for your understanding and consideration in this matter. This disease is devastating. Insurance coverage of IVIG would mean the difference of a typical child with a healthy, normal childhood or a child debilitated by a severe neurological condition that has drastically altered his/ her life. If a medical professional deems a medicine to be medically necessary, then insurance should be required to pay for that medicine. Families should not have to fight for years to get prior authorization to get their sick child proper medical care. This is a horrible condition that is treatable, but

unfortunately the treatment is unattainable for most families.

**Please vote in favor of
HB-447**

If you need any additional information, please feel free to contact me.

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