

February 4, 2019

Dear Delegate Carr,

My name is Jill Holtschneider and I am writing to you in regards to bill HB447. I would like to share my story with you. My daughter is 15 years old, (to protect her privacy I will refer to her as H), and has been struggling with P.A.N.D.A.S. for almost 5 years. She started with symptoms in April 2015 and started treatment for OCD in January 2017 with a therapist. Her therapy made no change in her OCD. In June 2017, H started therapy with a psychologist who after 3 months referred us to a child psychiatrist for medication that she felt my daughter needed. That psychiatrist put her on SSRI's and my child became a crazy person. She hurt herself, shaved her hair, and suffered greatly. NOTHING THEY DID HELPED HER AT ALL. In June 2018, we weaned her off everything and stopped seeing the doctors and she thankfully was not a danger to herself anymore, but went back to her sad life. In September 2018, we saw a psychologist who put the pieces together and with her medical history in mind, recognized her symptoms as P.A.N.D.A.S. We were referred to a pediatrician familiar with P.A.N.D.A.S. and she suggested we see a specialist, Dr M. Elizabeth Latimer located in Washington, D.C.

This was wonderful news and felt we were on our way to healing our daughter. Of course the downside is that like most P.A.N.D.A.S. specialists, Dr. Latimer does not accept insurance. With every appointment we have had, it involved a 7-9 hour day with travel, office time, etc, which is just plain torture to H. We made it work, paying out of pocket and receiving very little assistance with out of network insurance. We tried countless antibiotics and steroids and nothing has helped. So Dr. Latimer felt IVIG would be the best treatment for H. For a 15 year old weighing around 125 pounds, the cost is \$16,200. Our daughter's life is more important to us than anything, so we decided to drain our bank account to pay for it.

It was recommended that we go through the insurance route in a hope that we could get her much needed treatment covered. We filled out preauthorization paperwork, but felt we just could not wait any longer to get her treatment. Due to the fact that H was diagnosed so late, every day she goes without the proper treatment there is a greater chance that she will never see remission. She had her IVIG in July 2019. We were denied reimbursement because we were supposed to have the Dr's office do the paperwork, not us. They advised us to get a prior authorization. I have been trying to get this done since November 2019. When the Dr's office tried, they were advised that they are "working on" a new form specifically for P.A.N.D.A.S. patients. So while we are waiting for someone to come up with this form, we are very close to going beyond our timeframe of being considered for reimbursement. While the insurance company is making us play these silly games, my daughter's chances of healing are slipping away. She needs more treatment, but we have no idea how we are going to pay for it. We have no family resources and at such an extravagant price, we will have to start taking loans and God only knows what else.

H has managed to go to school and through the grace of God can somehow manage to get through her day. However when she gets home, all of the stress from "acting fine" at school has taken its toll and she lives like an animal. She cannot eat with her family due to noise sensitivity, most nights she sleeps on the floor like a dog, she cannot be touched by anyone, and the amount of paper towels and Kleenex she goes through just to get through the day is mind boggling. Her father, sister, and I are forced to just watch her suffer, trying desperately to get her the help that she needs. I think the worst part is that she is ashamed and embarrassed of her disorder. A health issue that is not her fault, that she cannot control, and she feels horrible about her self. I see the pain in her eyes and I watch her feeling more hopeless each day. If she had cancer, insurance

would pay for treatment. If she needed surgery, insurance would pay for that. Why should this disease be ignored?

There are so many children and families suffering because of this disease. Feeling helpless, feeling hopeless, feeling abused and dismissed. These children need help. Their families need help. We need our insurance companies to recognize that proper treatment will lead to healthy, functioning adults. If insurance companies are not made to take a hard look at their policies, these children will have a lifetime of medical issues. Insurance companies will be paying in network doctors to unsuccessfully treat these children into adulthood. If you compare the cost of proper treatment for P.A.N.D.A.S. against a lifetime of in network treatment that does not solve the underlying medical issues of this disease, the choice should be clear.

I realize that H may never be see remission. I also realize that we may never receive help from our insurance company. I will continue to speak out for this bill because it is needed. If not to help my daughter, then to help other children and their families.

Thank you for your time.

Sincerely,

Jill Holtschneider