



## PANDAS story

1 message

Tue, Jun 25, 2019 at 11:53 AM

To: pandas.mia@maryland.gov

Cc: charles.sydnor@house.state.md.us

Dear Maryland Insurance Administration,

I would like to share my daughter's story with you. [REDACTED] will turn 15 years old this month. [REDACTED] began acting strangely more than 4 years ago. Our family was dealing with the death of my mother, my job changes and subsequent summer class needed, and all of her end of elementary school activities. With everything going on, we noticed some weird behavior, but didn't pay too much attention to it. A year later, it was obvious she had OCD and we were referred to a therapist. She was diagnosed with OCD immediately and started weekly therapy. There were minor wins, but when one behavior got better, another one popped up. Our school counselor suggested PANDAS, but my primary doctor dismissed that possibility. We eventually switched to a psychologist and was then referred to a child psychiatrist who felt she was not improving because she needed to be on medication to help the anxiety, then she would be able to complete CBT therapy. Her meds were changed, and she became a different person. She was harming herself, shaved her head, and was slowly sinking into more desperate isolation. After six months of alarming behavior and meds being increased each month, we decided to wean her off the medication. We had been at this for 2 years and we were all done with the torture, we felt the OCD was bad enough to deal with and therapy was not helping.

After taking a few months to recharge, we sought out a psychologist who is known for her success with OCD. We went over her medical history and she suspected PANDAS. We were referred to a pediatrician with knowledge of PANDAS. She met with us and suggested bloodwork to confirm. She then referred us to Dr. Latimer, who is a PANDAS expert, in DC. At our initial appointment, she did an extensive evaluation and diagnosed Holly with PANDAS. She sent us for bloodwork and when we returned the next month, it backed up her diagnosis. [REDACTED] has low IGG levels and she suggested IVIG has the best success rate for children with [REDACTED] levels. Despite that, we asked for alternatives. In the past 6 months, [REDACTED] has been on antibiotics and 2 separate steroid bursts and they have not helped at all. IVIG is our last option.

We are already paying out of pocket to see Dr. Latimer. We went the conventional route, only saw doctors that are in network, doing everything they suggested. Not only has she not gotten better, she is progressively worse. [REDACTED] is almost 15 years old and due to her size, her IVIG will be approximately \$16,000. We have been fighting to have Dr. Latimer considered in network to no avail. We are in the process of requesting to have insurance help to pay for the IVIG which will get denied. My daughter has been suffering for 4 years. We cannot afford to wait any longer, so she will be having the IVIG in about one month.

My husband and I will do whatever it take to help our daughter be able to live her life again. My worry is if she must have more treatments, where will we get the money to pay for it. This disease has been around for many years now. There is lots of research, so many PANDAS children benefit from IVIG and similar treatments. I have heard the stories of hundreds of parents. I have sadly also heard of all the stories of children untreated because their insurance companies won't help. This is a disease that affects the brain. If these children aren't treated properly, what kind of future will they have? The children of today are the adults and future of tomorrow.

I urge you to look at the expense of having these children in therapies, on medications, etc. with insurance companies paying thousands of dollars because it is the only option for people that cannot pay out of pocket for treatment. So instead of treating the disease, you will treat the

symptoms for the rest of the child's life. Without proper PANDAS treatment, the symptoms will not go away.

I understand that insurance is a business and that business is to make money. If the choice is to pay for expensive PANDAS treatment, but have an outcome of remission and good health OR to ignore the illness and treat the symptoms with no good outcome for the rest of the patient's life, wouldn't it make more sense from a business perspective to treat the problem, get a remission, and then not have all these other bills?

I thank you for your time.

Sincerely,

A solid black rectangular box redacting the signature of the sender.