



PANDAS coverage

1 message

Mon, Jun 24, 2019 at 2:48 PM

[REDACTED]
To: "pandas.mia@maryland.gov" <pandas.mia@maryland.gov>

We are writing to you to respectfully request that you support the HB-15 bill requiring insurance coverage for pediatric autoimmune neuropsychiatric disorders. Over the last 2 1/2 years our family has been directly impacted by PANDAS/PANS. Two summers ago, something drastic happened to our daughter [REDACTED]. She was always the most loving, caring, happy, kind hearted child, loved to act, dance, sing, and was always a grade level above in school. Then our nightmare began. Over the course of a few weeks she began to layer her clothes. Before we could process what was going on she was up to 18 layers cutting into her hip bones. When we asked her why she would say because she felt like her skin was melting off. Then the OCD, rituals, insomnia, etc. set in. She started tapping everything. Some days she would have to tap a chair 50 times before she could get up. Everything was a counting game in her head and she had no control. This began to affect her at school too. Then the flareups of rage and suicidal thoughts appeared, almost like clockwork every 4-6 weeks. She would beg us to just let her die. Do you know the helplessness as a parent you feel having a "normal" child one day and having your child beg to die the next? It is the worst feeling in the world and I hope you never have to feel that pain. Yet no doctor could tell us what was wrong. We went to her pediatrician who mentioned PANDAS but told us she did not have strep so that was not a possibility. Over the next year and half, we went to psychiatrists, psychologists, occupational therapists for sensory processing disorder, immunologists, an ENT and had her tonsils and adenoids removed, did cognitive behavior therapy, put her on medication...nothing worked. Then we got into a PANDAS/PANS trial at NIH but unfortunately there was no longer funding for treatment. So, at the end of 2018 we paid \$1500 out of pocket to go to one of the best pediatric neurologists in the area who diagnosed her with PANDAS/PANS. Finally, we had an answer. We were thrilled. We were finally going to get our daughter the help she needed. She needed an IV treatment of Rituximab. The catch, insurance doesn't pay for it! We had made it so far only to not be able to afford the medicine she needed to finally get better. She needed two rounds costing a total of \$29,300. My husband is a teacher and I also work for the public-school system. We just didn't have that type of money. We discussed selling our house at that point, but it would take too long. Isabella, now 10 and missing a lot of school needed help asap. Before this she was a whole grade level above where she should be and now within a year and half she was testing a whole grade level below where she should be. Her reading, writing, math and attendance were being affected tremendously. We were now in meetings to get her an IEP. At this point my husband put his pride to the side and started a GoFundMe for \$29,300. We were one of the fortunate ones. We raised the money and she was able to get the treatment in January. We submitted everything to our insurance Carefirst Bluechoice and it was 100% denied even though this was the only doctor we could find in the area to treat our daughter. We are now in the appeal process. She is not 100% better yet but we are seeing tremendous improvement. Since 8 weeks post rituximab she has hardly had anymore suicidal thoughts, she is now attending school 5 days a week, her grades are going back up, she was nominated to be a patrol at school, she is back to joining extracurricular teams etc. Our hope is that she doesn't need any more treatment but we aren't sure at this point. However, even if she doesn't we will now fight for all the other children that do. This disease is real and is impacting not only our children but whole families. We have met so many families along the way that have had treatment and gotten 100% better, physically, emotionally and in the classroom. Please, we beg you, please support the HB-15 bill and make it easier for these children to receive the life-saving treatment prescribed by their doctors. Thank you in advance for your support.

[REDACTED]