

Sunday, November 8th, 2020

To the Ohio Health Committee,

In early 2019, our daughter was officially diagnosed with PANDAS/PANS, in that moment, the excruciating years our family had been through, all started to make more sense. I'd like to share our journey with you and explain the importance of this bill passing for our family and for the many other families and children suffering. Our daughter has gone through more than most adults I know over the last three years at the young age of 6 years old.

Our journey started back in December of 2017 when our child, who was a healthy and typically developing, took a 180 degree turn for the worse after a very common surgery (tonsillectomy and adenoid removal with a set of ear tubes placed). After this surgery, our daughter woke up the next day and quite literally "fell off the cliff". We worked for years with doctors and specialists of all kinds to get her healthy again and back to herself. Unfortunately, nothing on this journey has been easy or uncomplicated. No one seemed to know what went wrong or how to help her.

After this surgery, our daughter stopped eating all together, to the point where they had to insert an NG tube for 6 months. We even tried feeding therapy, Aerodigestive unit feeding clinics, nothing worked. They eventually had to surgically place a G tube which she's had for 2 years. She now has two GI teams and neither one could tell us why this happened nor was there any GI diagnosis given. She developed tics which she never had prior. They were typically vocal, mouth, and nasal tics that would come and go when she was exposed to illnesses or viruses. She began having rages that lasted for hours to the point of us almost having to admit her to the ER because she became so violent. Let me be clear here, our daughter is NOT a violent child, she is the sweetest, most compassionate and loving little soul you'd ever meet. We began OT thinking maybe it was sensory related issues, we saw no gains over a year, so we then tried behavioral therapies and medications. Each medication to help with the behaviors made her behavior worse or didn't help at all and her psychologist at one point told us one of her rage episodes that she saw was the most intense episodes she's ever seen in her career. She was then fitted for complex care equipment to help keep her safe when she'd enter a rage. She developed extreme anxiety and separation anxiety, so much so that there were many days we could not get her to school or we'd have to take her in hours later once she could calm herself out of panic modes. We never had anxiety issues prior to onset. Her speech also became noticeably different and we started speech therapy not knowing what was going on. Her processing of information felt off and she would get stuck in thoughts. She developed what we now know is OCD. Intense intrusive thoughts and very strange sleep disturbances which wax and waned in severity. We've completed sleep studies as well with no further insight. She develops these strange shiners under eyes every time her little body seems to be fighting something or her system has been impacted in some way. We thought they were allergies back in 2017/2018 but years of allergy testing ruled that out. I could go on and on in severe and abrupt changes that we witnessed right before our eyes, but I'll keep this as short as possible.

It became very clear that something internally was happening, and it also became very clear that no one at our local Children's Hospital was able to figure it out. We began getting second opinions and bringing in medical teams from other hospitals, even out of state, to evaluate her. It wasn't until we had multiple second sets of eyes on her that we learned what we were dealing with. We spun our wheels for over 2 years trying to uncover what in the world happened to our sweet little girl. Four different specialists that we went to for second opinions all came back with the exact same answer and diagnoses. "Your daughter has PANS/PANDAS". We had no idea what this was, and it took a lot of research and education

to fully grasp it all. We read cases, publications, and studies along with research completed on PANS/PANDAS and it felt like we were literally reading our daughters medical files. How had it taken SO long for someone to get to the bottom of all of this?

An immunologist we had been seeing put our daughter on antibiotics and we immediately saw the rages halt and the tics went away. Her tics would come back if she came down with something (ie. The Flu, strep, etc), but when she was not sick, the tics remained at bay. We have not had one rage episode since we've been on antibiotics which was in January of 2020. However, we are still in the throes of trying to work through many other intense issues that come with this diagnosis. Our daughter over the course of 3 years has gained a medical team of 22 specialists in over 5 cities and 2 states. That is how sick she has been. It is an EXHAUSTING journey, for all of us.

We have been told by 4 specialists that she needs IVIG treatments. Two have done their best to get coverage for us with our insurance company with no success. They have gone round and round with Cigna and we have personally spend hours a day on the phone between our nurse case manager, our cigna champion, and our benefits department. We have even been back and forth with my HR benefits department requesting assistance with the Cigna. The doctors have done appeals, peer to peer reviews between the medical director and the doctor with no success. The insurance company simply will not cover the treatments our daughter needs because they say it is "experimental" and they do not cover treatment for PANS/PANDAS.

Meanwhile, our daughter continues to suffer and is unable to get the treatment she needs. Our daughters' entire medical team is supportive in her moving forward with IVIG. They all have told us firsthand that they feel it is crucial for Ellory to start IVIG immediately.

Had we known what our daughter was dealing with years ago when she "fell off the cliff", we could have been much further ahead in treatments than where we are now. We've made some gains with her being on antibiotics, but it is just a band aid for the moment, and we have a **VERY** long way to go.

The most recent attempt to obtain IVIG treatment has still not gone well with Cigna. Our daughter's specialist has been hesitant to submit a prior auth for the IVIG with Cigna even though he feels it is urgent and imperative she receives treatment. His reason for being hesitant is due to a past experience with another patient. Cigna ended up not even covering the basic cost for him to carry out the treatment leaving him thousands of dollars in losses. He told us that the allowables with Cigna were lower than what Medicaid and medicare would even pay and that until Cigna could explain why this is the case and address this, that he didn't feel submitting a prior auth would make any sense nor did he want to commit to us that he could offer the treatments if it would leave him out thousands of dollars again. He said this knowing Cigna would deny the coverage all together which has been the case each time we've tried to get coverage. Cigna has also told us that any further prior authorizations would be met with denials. This leaves us with only one option, to pay out of pocket.

Because we have been unable to get coverage for the necessary treatments our daughter needs, we are now having to fundraise the costs of these very expensive treatments before we can proceed with moving forward. The cost of these treatments are astronomical and expecting any family to pay for these out of pocket is absurd. We are a family of 6 and my husband and I both work full time yet coming up with \$10,000-\$12,000 monthly or even every 3-6 months for her IVIG treatments alone is not feasible. This doesn't even touch her other out of pocket medical expenses.

This is a devastating situation for families and children who have suffered silently for years. This needs to change, and the time is now. The pure exhaustion this journey alone brings to families and children is enough to wear them out. Add in the hours a day on the phone with insurance companies advocating for coverage, and the 7-8-page letters writing and pleading to their insurance companies' multiple times, and the continual uphill battle overall to advocate for their children's needs. Simply put, it is one of the most gut-wrenching experiences I've ever had to walk through along with having to ask family and friends to help us fund treatments that we know she needs. It's unacceptable to allow a child to suffer when there is a clear treatment plan being outlined by more than a handful of doctors and specialists.

I beg of you and implore you to please think of our daughter who is only 6 years old, and to hear the desperation of my voice in this letter. Please pass this bill. Our families need you right now, our children need you.

Thank you again for taking time to hear our story and for your consideration on passing HB# 488.

Warm Regards,

Carolynn and Brian McClure