

Chairman Lipps, Vice Chair Holmes, and Ranking Member Liston, thank you for the opportunity today to testify on behalf of HB 189.

I am here to give my testimonial about my daughter Coraline and her journey to diagnosis and treatment of PANDAS/PANS. As to why I feel it is very important for PANDAS/PANS children receive proper medical treatment.

Coraline's story is a long one. Not the longest I suppose and not the worse but I feel it crucial to tell it to show how PANDAS/PANS children are often misdiagnosed and don't receive the treatment they need.

To begin the story I would like to tell you Coraline was a very intelligent thriving 6 year old middle child from an average family, prior to the onset of PANDAS (she actually as PANS). Coraline had no medical problems prior to her onset of PANS. Her father a police officer her mother a nurse. Her older sister 8 (no Prior diagnosis), her younger sister 3(also no Prior diagnosis) Coraline was an at times ornery middle child prior to her onset of PANDAS/PANS. Coraline was an amazingly functioning child. Even so much that she competed in multiple gymnastics events often bringing home many medals including a few 1st place all-round.

Coraline's first symptoms started around the beginning of August. She became very reluctant to even enter the Gym she had been going to since she was 18 months old. Initially my husband and I thought she's just tired. She had been going all summer to the gym for multiple days for multiple hours. But even after a "break" Cor still fought to go INTO the gym. She would put her leotard on willingly but could never commit to entering the locker room. We began to just call gymnastics a wash. And then the school year began. Coraline actually attended the first 2 days of school no problem (at least that I noticed). By the 3rd day it was no more. Cor could get dressed just like gymnast but couldn't go into the school without myself or my husband. Every day Coraline would wake up and do everything a child should do before school. Get dressed for school, pack her back pack, even walk out to the bus, but could never get on. So I would have to load her up and drive her to school. She would get in the car let me drive her to school, get out of the car walk into school. But she just couldn't let me go. At first we just thought she was being stubborn. But august became September and Coraline still wasn't going to school. We'd walk in and she would just stop talking and wouldn't stay in the classroom, let me walk away. One time I was able to slip away and Coraline just stood in the hallway screaming. I was told by the principal that Coraline was not "welcome" at the school and I should look in to homeschooling her. But both my husband and I knew there was something really wrong with Coraline.

We were able to get Coraline into a counselor. It went well for 2 visits and then Coraline started acting like she did with gymnastics, school and had even started to act the same way staying with my in laws (which she had done since birth). You could just see it wash over her. She would become nonverbal to actual questions. She would chant, screech, scream, claw. I had a children's ER doctor ask me if she was "on the spectrum ". We were urged by my mother in law to have her "committed" as Coraline had become a danger to herself. Coraline was so focus on staying with my husband and myself at all times that she had attempted to run into roads trying to chase us as we left for work. Try to jump out windows to get to my husband as he left for work, attempted to jump out of moving vehicles to get to us.

The ER was no help. We left that day with 2 pieces of paper. 1) To purchase a book about severe separation anxiety and the other a list of psychiatrists in stark County. We reside in medina. The counselor actually said to me as Cor was ramping up chanting and clawing at my husband "Go Home, Go home".... "I fear you may harm her". I was so taken back. Yet they had us leave. Only to find out a few years later they had flagged us with CSB. Yet gave us no assistance.

After MANY phone calls we found a psychiatrist that had an opening that wasn't 6 months out. We took Coraline to see him.... which was a catastrophe. Coraline couldn't get out of the car. The Dr wrote for Zoloft and Klonopin "to get her comfortable enough to get into school ". She also saw a

psychologist. Coraline continued to resist going anywhere without us or let us go anywhere without her. She started to exhibit new "ticks/ bizarre behaviors" sticking her earrings in her skin, wetting the bed, heck standing up from a chair and voiding randomly. Even her eyes her would be anisocoric (one pupil constricted the other dilated). They ended up upping her Zoloft to 75mg twice a day. We tried the Klonopin one time and only one time. Cor went from non-verbal chanting screaming to asking to die, to go to Jesus to end it all after taking the Klonopin. Coraline had started to exhibit other odd ticks

All this time the only way we could get Coraline to do anything was if we were with her. My husband would sit with her in school, in gymnastics. We had to take time off work. Still trying to figure out what happened to our baby and fix her.

We finally tried counseling again. As some had speculated Cor's anxiety was due to perhaps my husband's occupation. We truly did not know what to do. Our family and friends had basically deserted us as no one "could deal with Coraline ". All I could think of next was a priest. I needed my baby back. The counselor was sweet. Cor would not engage with her. Coraline sat on the floor and in OCD fashion organized crayons, with her back to the counselor but eyes on me and touching me. She always had to be that way eye contact and physical contact. The counselor asked if Coraline had been sick recently. Specifically strep. Which her sister had in May. But to our knowledge not Cor. She suggested Dr. Kriwinsky. I won't lie I was very skeptical.... but we had to try. We met with Dr (Jan.) January (I believe 20th) 2018. He listened to our story and explained PANDAS to us. He drew blood on Cor. Turns out she had pneumonia and hand foot and mouth. (Which I remember end of July girl scout summer camp. Cor got very sick for about 24 hours. High fever vomiting. I assumed it was the high temperatures, dehydration... as she was fine after that..... Except that was when she started to pull back from gymnastics.) . Dr Jan put Coraline on antibiotics that next visit. And we prayed they would work. Within not even 2 weeks Coraline was back. It was so amazing. She stayed on the antibiotics for approximately 4 months. (Another story for another day as far as people needing to be educated to PANS/PANDAS. We ended up in children's ER for several diarrhea with Cor in May. They treated me like I had Munchausen's and again misdiagnosed Coraline delaying proper treatment). Dr Jan had Cor off of Zoloft by the end of June. She was completely herself and medication free.

Every day it haunts us for fear of a relapse. To this day she has not relapsed. We thank God for that counselor and for Dr Jan. I have no idea where Coraline would be now without receiving the proper treatment she did. I am glad to be able to tell others our story so they do not have to go through what we did. PANDAS/PANS is very scary... but it's just as scary the lack of knowledge for proper treatment of it.

Thank you for reading her story.... we hope it will help others.