Hello, My name is Natalie Burke and my zip code is 97203. I live in Portland, OR with my husband and our three children. Our oldest son, who is 8 years old now, has PANS and he was misdiagnosed for 4 years. FOUR. YEARS. I'm not really sure where to begin in telling his story and our journey as a family navigating the healthcare system as it failed our child time and time again. This may be way too long to hold anyone's interest, so if that's the case, skip the first five or six paragraphs which are my toddler's life leading up to where he goes to a psychiatric hospital at age 6 because no one knows what to make of his symptoms. Here goes...

When Gavin was 2.5 years old, he came down with a series of illnesses while we traveled to Costa Rica on vacation. It started with a cold and then a high fever, a stomach virus, then finally a double ear infection that led to both ear drums rupturing. In the midst of this, he started to have these earth shattering tantrums, over nothing, over washing his hands a certain way, we didn't really know. We knew it was unusual, but as first time parents, we just figured this was a toddler phase that just happened to start when he was really sick. Looking back, it wasn't normal. It was the first flare of PANS for him. We brought it up with the pediatrician that he was having these rage fits that would go on and on, and then he'd stop as though it hadn't happened. And how he was repeating phrases over and over. And how he'd wake us up in the night, screaming and screaming from what we thought were night terrors, scream with terror and look right through us for 20 minutes to an hour, and have no memory of it in the morning. The pediatrician said we would keep OCD on our radar but that it was probably nothing. Over time, he settled down and then things would pop back up again. He'd start singing the same song each time he washed his hands or repeat a long string of words in order when he entered a room. Doctors just kept telling us it was probably just nothing. Toddler stuff that would go away. Lots of kids have night terrors, they'd say. So we suffered in mostly silence for another year and a half, until just before his 4th birthday. He'd had strep throat and a round of antibiotics, and just as he finished the antibiotics, he started having to urinate constantly. I'm not talking about something that can be ignored. This was my 4 year old, my sweet boy, who was going to the bathroom 18-30 times an hour. He would cry and beg us to make it stop. But he couldn't stop going to the bathroom to try. Imagine how terrifying and strange and disruptive to life that was for him and for us, as we frantically googled what was wrong, scouring every corner of the internet to try to find some answers. His pediatrician said to bring him in for an exam and a urine culture right away. We did and they ruled out a UTI. They set him up with their in house pediatric psychologist who evaluated him and said it couldn't be PANS/PANDAS because the onset wasn't sudden enough. Because we had been describing him as high strung and having OCD tendencies since he was 2.5, now he's 4 and it's no longer a sudden onset when this urinating thing started. The psychologist said it was probably just from the stress of turning 4, because he had expressed he was nervous about getting older. She said we'd just keep OCD on our radar but it was probably nothing.

It breaks my heart to think how many years my little boy suffered. How many nights he laid in bed, pleading with me to find him a doctor that could help this peeing problem stop. Flash forward to kindergarten and I went to his parent/teacher conference and his sweet teacher proudly opened his little journal to show me what my son had been writing and drawing during journal time. Gavin knew all his letters when he was two years old and had been writing letters very clearly at age 3 and 4. Now here he is in kindergarten, and his journal is full of nothing but scribbles and chicken scratch. Not a single legible thing in sight. It was startling and I didn't know what to say or think. His teacher hadn't known him when he was littler and he could write all his letters. I just thought maybe he was bored and that's why he was scribbling. Knowing what I know now about PANS/PANDAS, I know this was a decline in his fine motor skills. During his kindergarten year, he became so anxious and fearful that he stopped talking at school. He would run back and forth back and forth at recess, not talking to anyone. His teacher reports him becoming very withdrawn and shy during class. He never had behavioral problems at school, but as soon as he got home each day, he would unleash. He would change his underwear all night long because he was afraid "a drop of pee" got on them. He was still waking up every night with night terrors, screaming and panicking and have no memory of it the next day. His doctors said it was probably nothing but we'd keep ocd on our radar.

He was sick, literally, from September two weeks after kindergarten started, until February. He'd get one cold virus after the next, stomach viruses would turn into two solid weeks of diarrhea. He missed so much school. Our sweet boy was so hard to be around. He was obstinate and he would pick fights over nothing, he had to be right and control every situation. He was either panicking about peeing 25 times an hour or he was screaming and panicking that he hadn't wiped well enough. Once when he had diarrhea, he sat naked on the toilet for 8 hours because he was angry that maybe he still had poop on his bottom. EIGHT HOURS. This is not normal. This is not nothing. My poor sweet kindergarten boy sat on the toilet until his legs lost feeling because he was afraid his bottom wasn't clean, regardless of how much I reassured him he was clean.

It was at this point that his pediatrician referred us to a 3 visit psych consult at OHSU. In one visit, the psych department interviewed us as parents. In the next visit, they had Gavin in the room alone with them. He's charming, he's very sweet and bright and engaging. He was able to chat and engage and make it through 20 minutes of evaluation without incident. We left that visit, and 50 feet down the hall, he was right back to having massive meltdowns and OCD and rage. The third visit was when the psych department told us there was nothing wrong with him, maybe some minor anxiety and we could pick up a workbook on amazon.com to help with that. Also we could take parenting classes. A WORKBOOK ON AMAZON AND PARENTING CLASSES. I wept openly in that appointment and I think the doctors thought I was off my rocker. Really, I had that that this was it, this was where we were going to get some help. Our struggles would be seen. But no. Just get this workbook and take a parenting class.

A few weeks after the pysch consult, during the spring of kindergarten, things started to look up. The OCD symptoms and the rage and the fear and panic went away as soon as he started to bounce back from months of illness. We thought our boy was back and we breathed a sigh of relief. Even his teacher remarked that he seemed lighter and happier, and like his old self that she had known at the first couple weeks of the school year, before he started getting sick all the time. This good time lasted about 3 weeks and then he was exposed to hand foot and mouth, and before the rash broke, he had what I can only describe as a mental breakdown at age 5.5. Out of nowhere the screaming night terrors came back. He was paralyzed in panic about getting a drop of pee on his underwear. He was back to going to the restroom every few minutes. He screamed in terror about wanting to cut his penis off with a shard of glass so that this would stop bothering him. What 5 year old has these kinds of thoughts? A couple days into this, he had a fever and a rash. Looking back, we believe the hand/foot/mouth set the PANS wheels in motion again. His pediatrician made no connections between all this illness and the psychiatric symptoms he was having. We're now at year 3 of misdiagnosis. They started him on SSRI medication at this time, due to the terror and panic and the fact that he started having intrusive thoughts. All the while, my sweet boy is still pleading with us to find a doctor who can stop all of this from happening.

Another 6 months goes by. We don't even see our Gavin's personality anymore, except in a couple of one or two minute glimpses per day. His pupils are huge and his eyes have a glassy look that is unmistakable as the eyes of someone with brain inflammation. We didn't know it at the time, but now we do. He's hyper, bouncing off the walls, he changes his underwear 3-5 times before he can settle in for sleep at night. He's exhausted. He's waking up screaming in panic at night and he doesn't remember it in the morning. He's going to the bathroom so much at school that he's missing out on learning time. His well meaning teacher asks him to hold it unless it's an emergency. So my sweet rule following boy holds it all day long and is about to pee his pants when I pick him up each day because he wants to do what his teacher said. And it's not exactly an emergency, right mom? He repeats nonsense words and phrases and asks me 500 times a day if I love him or hate him. He obsesses about whether or not he said a swear word aloud (he never did but he fixates on what if he accidentally did). All the doctors say "he doesn't fit into an easy diagnosis" and "hmmm he's not responding to medication and therapy the way we'd expect" and we just keep waiting and hoping for someone to have an answer, someone to tell us how to fix this. They all say it's too early to diagnose. He's young, we're not sure what this is. This could be ocd or anxiety or bipolar or ODD or adhd or a combination of all these things.

He's six and a half years old at this point. He gets a stomach virus on winter break. His ocd comes on hard. He's raging. He's manic. He's stripping his clothes off, down to underwear, in the the backyard in a snowstorm. My sweetheart loving, kind boy is screaming at me to call the police and that he's going to kill me. He's walking on the countertops, jumping up and down on the table screaming at us and I'm huddled in the bathroom with our two year old and our infant, on the phone with his psychologist and his behavioral pediatrician. I don't know what to do and this is scary and I'm telling you something is really wrong. They tell me to call 911 and get him admitted. I'm terrified. He's SIX years old. He's a tiny little boy and something is very wrong and no one can tell us what it is. My husband manages to get him to Willamette Falls Hospital's emergency room, because this is where we've been told to take him, to get him admitted into a pediatric psych facility. They wait there for four hours. The doctor comes in for 5 minutes. The doctor says he's just a kid having a fit, get him a granola bar from the vending machine, and head on home. Here's a pamphlet on oppositional defiant disorder. (sidenote INSURANCE- we had to pay a $250 fee on top of our copay for the ER visit because we went to the emergency room and didn't get admitted. That's how our insurance works, I assume to deter people from going to the ER when they don't really need to) Seriously this is what happened. We're dumbfounded. We don't know what to do or who to call. We come home and he rages and acts manic for another few days. We go to his regularly scheduled psychologist visit and he comes apart there in the office. He does the catatonic rage we've been trying to tell her about. The doctor is shaken and after 45 minutes of restraining him, she tells us we need to take him to the emergency room, a different emergency room, one with pediatric doctors on staff, and we need to insist that he's admitted this time. We get him into the car and drive to the OHSU pediatric emergency room. They evaluate him and the psychiatrist listens to our story and says "well at least we can rule out PANS/PANDAS because it sounds like the onset wasn't sudden". She tells me how the system of getting a bed a pediatric inpatient facility will work. We will stay with him, around the clock, as parents, in the emergency room at OHSU until a bed opens up. It could be a day, it could be two weeks. Think about how disruptive that is to a family. And to a child. We lived in a small room at the OHSU emergency department for 6 nights. One parent would go to work while the other stayed in the ER with Gavin. Then we'd switch and the other parent would run home to feed the dog and go to night shift at work. Our two year old went to grandma's house for the week and we juggled our infant in the emergency room for 6 days. The call comes on the sixth day that he is to be transported by a secure car to willamette falls hospital. It's like a police car but it's a private company that transports from hospital to hospital. This is something that we'll later have to appeal to have our insurance cover it. He's 6 years old. He's no longer asking questions about what's wrong or how can we make it better. He's accepted that this is who he is now and he's asking us if he's real. "Am I a real boy? I feel like I might not be real"

We check our 6 year old, who's never spent a night away from us, into a psychiatric facility. It's terrifying but at least this is it, at least we'll get some answers and some help, right? The head psychiatrist tells us at least we can rule out PANS/PANDAS because he's always been this way, right? It's not sudden onset, so at least we don't have to go down the PANS/PANDAS rabbit hole. They do every test in the book. They lock his bathroom door so he can't go to the bathroom a million times when he's in his room for the night. They call me to say they're going to have a doctor do a psychiatric evaluation. The hospital verifies that our insurance will cover it, but then the receptionist calls to say the doctor is concerned he won't get paid, so can I also call to verify that insurance will pay? I'm spending hours driving to and from the psych hospital every day to visit him and I'm caring for a two year old and an infant, but sure, I'll call to verify it. I'm on the phone for two hours with insurance. They say it will be covered and they don't understand why the doctor isn't taking their word for it. The day of the evaluation comes and the doctor himself calls me to ask if I will pay him if insurance doesn't. We have providence insurance. This is a providence hospital. I don't understand why they keep calling me to ask me these questions. He does the evaluation and then he calls me back to say "your son is hard to figure out. What do YOU think is going on?" He then tells me if he had to make a diagnosis, he'd say OCD and tourette syndrome, which is characterized by tics. Our son has never had a tic. He says Gavin is too young to diagnose. We'll just keep watching him and things will become clearer as he gets older. A week into his stay at the psych hospital, the staff calls to say he's ready to be picked up. They don't have time to do the normal discharge meeting, but they can have the doctor call me. We're dumbfounded again. Our son has now been in the hospital for nearly two weeks (6 days in the ER and a week in psychiatric inpatient) and we have no diagnosis. No plan. No answers. This was supposed to be our last resort, our "if it gets really bad, we can always take him to the hospital" and now here we were, at the end of the road and we have no more answers than we started with, We pick him up and as soon as we get home, he's raging. We get the call from the doctor at willamette falls, the follow up since they didn't have time to do it in person. You know what she said to me? She said "we don't know what's wrong with him. He doesn't fit any of the usual diagnoses. I recommend you make a room or a closet in your house that's safe for him, that you can lock from the outside, and bring him back here later on if you need to." Can you imagine someone saying that about your sweet 6 year old child, your child who is ill and no one knows what to call this illness? This hospital stay was almost two years ago now. We have great insurance. Even still, we just finished paying off the monthly payments that we owed Willamette Falls hospital for keeping our child for a week and then telling us they don't know what's wrong but you should make a safe room and then just bring him back if it gets to be too much.

A month later, we had an appointment with a naturopathic physician who specializes in PANS/PANDAS. Two weeks after that, our boy did a 180. As soon as we started treating him for PANS, his OCD vanished. The glazed look in his eyes and the dilated pupils went back to normal. His fine motor skills came back and his teacher is no longer concerned that he has trouble holding a pencil. The rash on his hands disappeared and it never came back. He doesn't wake up screaming in terror anymore, and he's not exhausted and sad and angry. I wish I could say all is 100% and that this is behind us, but it's not quite. He still has a little bump in the road whenever he gets sick. But it goes away after a few days, and it doesn't rule our lives the way it used to. Life has been so much better for Gavin and for us as his parents now that we actually know what we're fighting. Things could have been so much easier. It hurts my heart to think of the 4 years that we wasted, looking for answers in all the wrong places, and not even entertaining the thought of PANS/PANDAS just because all the professionals we trusted said "oh it can't be that. That's so rare. That's a rabbit hole. That might not even be real. No, he's always been like this" You start to believe it. You start to doubt and second guess your own experiences and intuition. We need to raise awareness among families and educators and healthcare professionals that this IS real. This is treatable. This doesn't always fit into a neat box. It's hard, it's mysterious and doesn't have easy answers, but rather than saying "oh that's so rare" and "that's a rabbit hole, you don't want to go down that path for diagnosis" We need our doctors to listen and to admit when they don't know how to treat something, but instead refer us to someone who does know. We also need insurance companies to cover PANS/PANDAS as a real medical condition, because that's what it is. Our kids shouldn't be denied treatment because there's no diagnosis code for their illness. I could go on and on, and I have, and if you're still reading our story, you're a saint. I hope this sheds some light on what families go through and how much easier this all could have been if someone had listened from the start. If someone had encouraged us to do some reading about PANS/PANDAS and draw our own conclusions if it seemed to fit or not. It does children and families like ours such a disservice to have a doctor rule something out without even really evaluating the situation.

Thanks so much for your time,
Natalie Burke and family
Portland, OR