

PANDAS Insurance Bill Testimony  
House HHS Committee  
12/14/2020  
Andi Bonge BSEd, MOT, OTR/L

Good morning.

My name is Andi Bonge. I have a Bachelor of Science degree in education and a Master's degree in occupational therapy. I am board certified and am licensed to practice occupational therapy in the state of Missouri. I have been practicing for 24 years and have worked in a professional capacity with children for almost 30 years. I am here to tell you about my personal and professional experience with children who have neuropsychiatric symptoms.

In the year 2000, I embarked on a new position in which I specialized with children with sensory and behavioral disorders. This position was extraordinary because I was able to be imbedded in a classroom with 8 children for the whole day. I was able to see the full expression of their behavioral and emotional dysregulation through the day, as well as to develop an in-depth understanding of their personal learning challenges. I worked with four other consummate professionals on a multi-disciplinary team. We shared a love of application of research into multi-modal treatment and teaching strategies to help remediate symptoms and developmental deficits.

In 2010, I took the position of occupational therapy supervisor at a private behavioral academy. The students in this school were placed there by metro school districts who could not manage their behavioral and educational needs. It was this year that my youngest daughter, aged four, developed PANDAS. Her symptoms started on a sunny afternoon that September and presented as a tantrum that lasted over 30 minutes--atypical of her typically sunny disposition. I didn't ever think about this tantrum during the busy work of managing children, a household and a career as her symptoms began to multiply and worsen until she received the diagnosis from a local MAPS doctor in 2014. By that time, she also met the criteria for Autism Level I.

My purpose in telling you my background is to demonstrate that I have had the personal and professional opportunity to witness how symptoms as listed in the diagnostic manual can present in the home and the classroom; and how acute onset can be followed by a more insidious decline that can be missed by medical practitioners and parents who are bewildered by the behavioral changes taking place in their child. This is creating a big gap in children being identified.

Diagnostic criterion for PANDAS (NIMH,2020) are:

- Presence of OCD, tic disorder or both
- Pediatric onset
- Episodic course of symptom severity
- Association with Group A strep
- Association of neurological abnormalities such as physical or hyperactivity, or unusual jerky movements that are not in the child's control
- Abrupt onset or worsening symptoms

Other symptoms that are commonly displayed in conjunction with OCD or tic disorder:

- Hyperactivity, inattention or fidgeting
- Separation anxiety
- Mood changes: irritability, sadness, lability
- Trouble sleeping
- Nighttime bed-wetting, frequent daytime urination or both
- Changes in motor skills
- Joint pain

In my experience with my child and the children with whom I work, PANDAS symptoms develop during developmental periods during which a typical child may exhibit odd or maladaptive behaviors--think of the "terrible twos" or the oppositional behaviors that can occur with increasing language skills at age four. Mild symptoms at onset can be dismissed as a "stage" or "phase" through which the child will quickly pass, however they can become significant as the disease process continues. I worked with several individuals who presented with developmental disabilities/coordination issues that I believe have missed PANDAS diagnoses.

One child presented with bilateral coordination deficits, including articulation errors for which he was seeing the speech-language pathologist. He was well-below age in the development of fine motor and gross motor skills. He also had difficulty coordinating both sides of the body smoothly to complete tasks such as running and jumping and manipulating scissors to cut while holding paper. He had difficulty remaining seated to complete a task and sleeping was at times poor. He exhibited a bilateral eye blinking tic. He had poor balance control, weak muscle tone, and primitive reflex retention. He had a fear of going down steps which could trigger major tantrums and an obsession with keys which led to the behavior of taking keys found in the household and hiding them. This behavior could lead to significant household upset.

We worked for two years with improvement in symptoms and skills, but not full remediation. One winter, he was out of school for two weeks with pneumonia. On his first day back into therapy, he bounded down to the basement for therapy without hesitation at the top of the stairs. He jumped the final two steps, walked the balance line without faltering and skipped the rest of the way to the room. We completed his handwriting work which was performed with

smooth, automatic movements; there were no motor deficits apparent that day. On a hunch, I had him perform balance tasks and he could stand on each foot for several seconds when his typical performance was around one to two seconds each. Following our session, I contacted his mom to tell her of the amazing growth in skills since his last session. She was happy and chatted about his progress and at the end of our conversation said excitedly, "Imagine! All this after two weeks with pneumonia, antibiotics and steroid shots!"

Later, I reflected on her comment and gave her information regarding PANDAS to take to her doctor. Upon her request, I attended a doctor appointment with her and her son to talk about what had happened. I said little as the doctor dismissed tics as common (they are more common than 20 years ago, but they are not normal) and development happening in spikes. When asked my opinion, I stated that developmental disabilities do not remit with antibiotics and steroids, but the parent did not receive support from that doc and soon left the practice. Unfortunately, the child began slowly losing many of the gains that he had after his illness, although his key obsession never returned and stairs were no longer anxiety producing, and he was dismissed from therapy the following year.

The NIMH estimates that PANDAS impacts 1:200 children. Dr. Rosario Trifiletti of the PANDAS/PANS Institute in Ramsey, NJ estimates that the number of children is likely 1:50. From my professional experience in public school districts, and my personal experience of neighborhood parents contacting me regarding strange symptoms in their children, I would agree. I see children with mild symptom clusters and other diagnoses frequently.

One child that was referred to me for sensory strategies to include in his 504 had these issues. He was a gifted child that exhibited a significant need for movement within his classroom, but demonstrated most of his difficulty behaviors only at home. (This is not uncommon with PANDAS kids, as many can keep it together during the day causing considerable stress.) When I observed him in his classroom, he demonstrated many behaviors such as laying on the floor and scooting along his back, bouncing and catching a ball, talking to himself and continually rearranging his desk and chair which was placed in the back for obvious reasons. The teacher is a veteran educator with special education experience, so she deftly continued instruction during all these distractions and he was able to quickly answer all questions when called upon. He was able to engage easily and successfully with classmates when an indoor recess was announced.

Interestingly, his parents reported horrific behavior in the home. Tantrums and outbursts, aggression over minor issues and extreme rigidity. He also despaired that no one liked him and he didn't have any friends. He was labeled with several psychological diagnoses including ADHD, ODD and Anxiety Disorder and was on psych medication. This is typical of PANDAS kids. I wanted to rule out possible PANDAS, so I performed a quick motor screening on him and he demonstrated choreiform movements. I informed the parents of my suspicions, but have no knowledge if he received a diagnosis and treatment as they moved shortly after. However, based on the experience with my own daughter, and that of families I know in the PANDAS community in our metro, it is unlikely that he has.

As I mentioned previously, my own daughter's acute onset would not be recognized for what it was until she was diagnosed at age eight—four years after onset. Her symptoms were varied, as they developed; though they relapsed and remitted, they grew increasingly more debilitating. As the number of tantrums increased, she spent more time in behavioral interventions. She developed motor tics, coordination issues, sleep disturbances, sensory processing problems and learning issues in addition to the severe behavioral problems. I became a therapist at home and utilized much of my professional experience. I implemented reward charts for good behavior, used time out for maladaptive behavior and multiple sensory interventions with a predictable schedule to create an environment more supportive of her diminishing processing and motor capacities. I held her down for hygiene tasks such as hair washing and nail cutting, put her on a toileting schedule and watched fluid intake as she began having difficulty holding her urine. I re-taught motor skills that she lost or were not developing. In public, I remained alert for issues that could create a tantrum or upset and navigated through them. We spent over \$100,000 dollars (out-of-pocket) on interventions including occupational therapy, sensory integration therapy, psychological and psychiatric services and medical interventions to stabilize her decline. She saw eleven professionals in medical and allied fields before receiving the correct diagnosis. Before my daughter's diagnosis in 2014, I had never heard of PANDAS. Since I have become aware and experienced difficulties in accessing accurate diagnosis and effective treatment, I have also seen how these symptoms can be dismissed as developmental issues by an uneducated medical community.

Since then, the learning curve has been steep, and I am thankful for the knowledge that I have gained from our experience and research to apply to the children with whom I work. It is for them that I have the privilege of speaking. I thank you for hearing us today and our request to draft a bill to provide insurance coverage for children in the state of Kansas with this disorder.