

Our Daughter's Recent Journey: As a young child, my daughter was frequently ill with ear infections, sinus infections, strep throat. She was also susceptible to colds and flu during the flu season. Treatment included many rounds of antibiotics.

She was seen by an allergist/immunologist regularly for treatment. Dairy elimination was tried, with little impact. There was no diagnosis, though symptoms persisted on and off for years.

Our daughter displayed fatigue and mood swings in high school, along with depression and anxiety. Brain fog was also a concern. School was once enjoyable and easy to navigate, it became more challenging over time.

September 2020 our daughter moved to college in Arkansas.

It appeared that with the addition of the stress of college and covid, her symptoms increased - brain fog, anxiety, fatigue and mood swings.

(Our oldest daughter also has immune issues, which presented a full-blown case her first semester of college as well. Symptoms were different, but still impactful – fatigue, brain fog, food allergies, leaky gut. She did not ever get a diagnosis and continues to have periodic symptoms.)

In October of 2020, our daughter began experiencing tics. She was diagnosed with Sydenham's Chorea by an urgent care doctor in Overland Park. Penicillin and a series of prednisone medication was prescribed. For follow up, we saw a doctor from SpringHill.

The tics (uncontrolled verbal, arm, and leg movements) began to worsen, guanfacine was prescribed to manage them. Fatigue and mood swings, OCD like behaviors, depression and anxiety have increased.

In October we saw a neurologist at a prominent movement disorder clinic. He indicated that he did not think our daughter had Sydenham's Chorea because of the type of tics she was experiencing. He also stated that he had heard of PANDAS but did not really believe in it or that this could be a possibility with our daughter's symptoms. We saw the doctor for less than 15 minutes. The doctor ordered an MRI, which is scheduled for Monday, 12/21. He recommended we stay with the current medicine protocol, guanfacine and added an order for cognitive behavior therapy. He stated that he did not really know anyone who could do the therapy, as their therapist was out; we should ask our doctor. No other diagnosis or treatment was offered.

Following the neurology appointment, our daughter was referred to Dr. Wang in Overland Park by another physician. We are in the process of scheduling that appointment.

Our daughter is still experiencing the tics and other symptoms mentioned. The guanfacine has helped some but caused dizziness and possibly fatigue.

We do not have a diagnosis or a treatment plan. At this time, I do not know of any other physicians who will explore immune issues with our family.

In the meantime, our daughter is experiencing tics, fatigue, brain fog anxiety and mood swings. Completing school was challenging, with many missed classes and difficulty completing assignments due to an inability to focus, complete tasks and control her tics. She currently has reduced her activities to being home to rest and going to work, with occasional social activities.

We do not know what the spring semester and beyond hold for our daughter, as we are not able to determine a diagnosis and a treatment plan.

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