

My name is Trisha Mount, and I am a nurse, Air Force veteran, and mother of 4 children. Today I'd like to tell you about my teenage daughter, Katie. Katie grew up playing softball; she was a lefty pitcher and played on a travel fastpitch team for several years. When she stopped playing softball, she easily picked up figure skating. She has always been very artistic, mature for her age, and was proud of her straight A's. By age 15, Katie was excelling in school; she was in all honors classes and had the highest GPA in her class. Even though she was only a ninth grader, she had already planned out her career and hoped to attend the med school program at OSU to become a pediatric surgeon.

On October 4, 2020, Katie woke up a different person. She was suddenly so anxious that she could not tolerate being in public. She could no longer attend school in person. Her cognitive function test showed that she went from a college reading comprehension level to a fourth grade reading level. She had to drop honors classes, as she could not do basic elementary math. She was having disturbing intrusive thoughts; she said 80% of her thoughts were not her own, they were just coming into her head from somewhere else. She was having self-harm thoughts that were so overwhelming she felt the need to cut herself multiple times per day. Overnight, Katie went from a totally normal child to being in suicide precautions in the inpatient psych unit, as this was the only way we could keep her safe from herself. She was diagnosed with obsessive compulsive disorder, which made no sense to me, because she had never displayed any symptoms of OCD in the past. She was evaluated by an immunologist, and the only way he could confirm the diagnosis was to have a Cunningham panel test done to prove she had antibody activity in the receptors in her brain, which was \$1000 out of pocket. The test is not covered by insurance. With the positive Cunningham panel and a positive strep titer, we had a diagnosis of PANDAS.

In January 2021 she had 6 plasmapheresis treatments, which helped just enough to keep her out of the hospital. In May, she had a flareup and was readmitted to inpatient psych after she refused to eat for seven days. Avoidant and restrictive food intake disorder is yet another symptom of the illness. She was in the hospital for six weeks this time, and received another six plasmapheresis treatments, which again helped, just enough to keep her out of the hospital.

In September, after waiting a few months for insurance approval due to previous denial, she started monthly IVIG. After her fourth monthly IVIG dose, after over a year of being sick, she was finally starting to improve and was able to get a job and think clearly enough to complete her online schoolwork. This gave us hope, that if we could just keep her on the monthly IVIG then she might be able to go back to school for her senior year. I was grateful to have my daughter back for almost two months. Unfortunately January 1st is when insurance "resets." This required reapproval for the IVIG, which took several weeks. A "denial," then a few weeks later a "request for more information," then a few weeks after that we were finally approved again in April. But, after 3 months without IVIG, she was already back to being psychologically unstable. The intrusive thoughts were overwhelming her, the anxiety was so bad she could no

longer work, and she wasn't able to process information well enough to complete any of her schoolwork the entire spring quarter.

I feel as if we are at the mercy of the insurance company, and my daughter's life is dependent on their approval or denial for treatment. She HAS attempted suicide. In my eyes, her illness could NOT get any more severe than this. It saddens me to think of all the children who may have succeeded in taking their own lives while waiting months for the insurance company to approve the treatment that could have saved them. Who makes the decision whether or not our children can get the treatment their doctor has ordered? Why is the exact same medication approved one time and denied the next? This is a very complex illness with extreme symptoms, and I agree with the proposal to require insurance companies to cover treatments for PANS/PANDAS, because these children need consistent treatments, and denying or delaying their medication for any length of time can result in devastating outcomes.

Thank you for your time.

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