



Julian Vilaranda, who was diagnosed with PANDAS in 2015, continued to be plagued by symptoms despite treatments. Now, with IVIG therapy, he is showing positive change, and he and his family have hope for his future.

IN EARLY 2015, Ontario, Canada, residents Amelia and Carlos Vilaranda were the parents of two healthy and active sons, 10-year-old Julian and 15-year-old Jayden. But life for this family of four was about to radically change, when just prior to Easter, Julian developed a sudden onset of debilitating obsessive compulsive disorder (OCD). After weeks with no answers, Amelia says her son was finally diagnosed with pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS). Following two years of hit-and-miss treatments, last fall, the Vilarandas paid out of pocket to have Julian's blood sent to a special lab in Oklahoma for intravenous immune globulin (IVIG) eligibility testing, and in November, they received the good news that Julian's treatment was approved.

PROFILE: Julian Vilaranda

By Trudie Mitschang

Trudie: Were there any health events leading up to Julian's symptoms?

Amelia: In August 2012, during a summer vacation in Cuba, Julian caught a serious case of impetigo on his nose. Upon returning home, we visited the doctor because the infection wasn't going away. Unfortunately, he was only treated with a topical cream and not an antibiotic. With time, the infection went away only to return at least monthly. Julian also seemed to develop seasonal allergies, often complaining about itchy eyes, and his nose would get congested, causing sinus issues. We now believe impetigo caused by strep bacteria might have been the trigger to his misdirected immune response.

Trudie: What was Julian's initial diagnosis?

Amelia: We visited the family doctor for the first time in March 2015 for the OCD symptoms. The doctor performed a routine check-up and said that maybe OCD was just part of his personality. We left the office with no recommendation or treatment plan. That same week, Julian's symptoms skyrocketed. His anxiety level was through the roof, and he began to have horrible intrusive thoughts. At times, he would hit his head on the floor in desperation. That's when I requested a referral.

Trudie: What happened next?

Amelia: The next doctor diagnosed him with anxiety and prescribed a very low dose of fluoxetine (Prozac, Sarafem).

Upon hearing this medicine could cause him to become aggressive, Julian refused to take it. So, instead, we tried a natural product called LTO3, and it did calm him down, but not as much as we hoped. His anxiety kept increasing, he became terrified of going to school, and he became desperate and said he no longer wanted to live like this. The first time I heard my baby say these words, it was like knives stabbing me in the heart. I called Chatham-Kent Children's Services, and a crisis social worker detected we were dealing with more than a mental illness. She told us we needed to take our son to the emergency room (ER) immediately.

Trudie: When was Julian diagnosed with PANDAS?

Amelia: After our trip to the ER, we were referred to Wendy Edwards, MD, who saw us the next day. She was the first to diagnose PANDAS.

Trudie: What was Julian's treatment plan?

Amelia: He was prescribed azithromycin and a very low dose of fluoxetine, and he experienced symptom relief almost immediately. He was on antibiotics for a couple of months, initially on a treatment dose and then prophylactically. He finished the school year successfully and did so well that, halfway through the summer, I took him off antibiotics to give his body a break. In retrospect, that was probably my biggest mistake.

Trudie: When did things get worse?

Amelia: His health declined rapidly in fall 2016. We immediately put Julian back on antibiotics, but this time, it didn't work. We added many supplements and alternative therapies, but nothing really brought him back to baseline. He became so severe that he could no longer attend school or leave the house. His pediatrician suggested we try an antiviral, and for a short while, he started to feel some relief, but then he would relapse. We started to wonder if one of us was a strep carrier. We all got tested and, sure enough, Jayden was a carrier. Because Julian's symptoms were so severe, he became suicidal, and his doctor prescribed him 30 days of a steroid taper. The first 15 days were absolutely horrible with rages and increased OCD. As we started to decrease the dose, Julian finally began to show some progress. Since none of the other antibiotics we tried worked for him, we began to suspect his strep was hiding in his gut. His doctor kept him on an antiviral and added rifaximin, an antibiotic that targets only gut bacteria. Jayden was also put on azithromycin and rifampin to get rid of the stubborn strep still hiding somewhere in him. This combination of Jayden's treatment and Julian's new antibiotic seemed to be game-changers. He finally started to make progress, but the minute he came in contact with someone sick, he would experience an immediate increase of symptoms.

Trudie: When did you first consider IVIG?

Amelia: We first considered IVIG over the summer, when he had been housebound for months. He was getting desperate and losing hope that he would ever get his childhood back, and his

pediatrician agreed he was a good candidate for IVIG. Thankfully, he was approved, and the treatment is covered by the Ontario Health Insurance Plan. He had his first infusion in November 2017.

Trudie: Tell us about his infusion.

Amelia: Julian's first IVIG treatment took place in our local hospital. He received high-dose IVIG after being well-hydrated for several hours. Half an hour before the infusion, he was given 30 ml of Benadryl to prevent any possible allergic reactions. The first infusion took approximately six hours, and he was kept on IV hydration throughout the night. His second infusion took approximately five hours. Julian did really well and had no side effects other than a mild headache before he left the hospital. The first night home, his headache became a migraine, and we treated him with Advil and lots of hydration.

Amelia: I researched everything I could to help me understand the journey we were about to embark on. I joined various Facebook support groups. I attended a screening of the film "My Kid is Not Crazy," followed by a presentation by Ayla Wilson, ND, a naturopathic doctor treating this condition in Vancouver, B.C., Canada. I watched several YouTube video conferences featuring the top U.S. neurologists and pediatricians treating this illness. I have spent many late nights and full days in front of the computer trying to wrap my brain around the complexity of this illness and the treatment plans available.

Trudie: What advice do you have for parents who suspect PANDAS?

Amelia: If you notice a change of behavior in your children without any apparent reason, seek answers. Visit the doctor's office and demand testing. I can't stress

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Trudie: How did he respond to IVIG treatment?

Amelia: The very next day, his PANDAS symptoms started to decrease. His OCD wasn't as severe, and his mood was more stable. He was able to go upstairs to his room without having to come back down and up again. I know it is very early, but we are already seeing glimpses of positive change. The best part is he is noticing these changes himself, and hope for healing is finally coming back to him.

Trudie: How have you educated yourself about Julian's condition?

enough the importance of knowledge. Knowledge is power! Spend the time doing the research and educating yourself on their illness and treatment choices. I would also recommend journaling everything. It is easy to see progress or regression on different treatments this way. Lastly, remember PANDAS affects the whole child, so forming a team of professionals who are willing to work with you and with each other is extremely important. ■

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