

# The FACE of PANS/PANDAS in Kansas



## Luke Musselman

20 years old

Clifton, KS

Freshman, Cloud County Community College

### BACKGROUND OF DIAGNOSIS

In 8th grade, I went from being a teenager with High Functioning Autism to being debilitated enough I couldn't do my homework, take care of myself or walk and eat by myself. I was officially diagnosed with **PANS (Pediatric Acute onset Neuropsychiatric Syndrome)** in July 2017. My symptoms started when I was 14 years old in February 2016 by retracing homework assignments. I progressively became worse and more shut down with extreme OCD (Obsessive Compulsive Disorder) after school ended. I became very resistant in taking medicine and it was hard to even get out of bed in the mornings. I was seeing a psychologist and psychiatrist, but unfortunately it wasn't enough.

### TRYING TO FIND PROVIDERS

In June 2016, I went to Stormont Vail West in Topeka, and Children's Mercy in Kansas City. Unfortunately, neither was the right provider to get to the root of my extreme OCD. From November 2016 through August 2017, I was away from home at LakeMary in Paola, known as a psychiatric residential treatment facility (PRTF).

My parents were extremely worried for my overall health. We finally found an Immunologist in Omaha, NE who treated PANS/PANDAS. He officially diagnosed me with PANS through a clinical diagnosis based on my symptoms. I started on antibiotics and steroids. Throughout my treatment, I've also seen neurologists and numerous behavior therapists. I still see a rheumatologist in Overland Park who is currently the ordering physician for my IVIG (Intravenous Immunoglobulin) infusions. My immunologist in Omaha who had also prescribed my IVIG retired in December 2021. My first IVIG treatment was October 2018 and I am still receiving them. The IVIG treatments reset my immune system and prevent my own antibodies from attacking healthy brain cells. This brain inflammation is what causes my extreme OCD.

### OVERCOMING ADVERSITY AND GOING FORWARD

Despite extreme challenges with my medical condition, I was able to overcome and achieve my goals after the proper diagnosis and treatment. With my condition, I lost a year in school. But, I was finally able to graduate from high school in May 2021. These past two years since I have gotten better, I have been able to raise awareness for the condition. I've written and given a speech about PANS for my high school speech class. I have advocated at the State Capitol in Topeka at a PANS/PANDAS Awareness Day. I also testified before a committee in the Kansas Legislature requesting increased providers in the state for PANS/PANDAS and insurance coverage for it to help other kids and families like us. I was honored to be one of four state finalists in 2020 for my 4-H Self-Determined Project about my PANS condition. I was also able to earn the 4-H Key Award which is one of the highest awards a member can achieve. I am now attending college in Concordia at Cloud County majoring in General Agriculture/Meteorology.