My name is Mason Lough, I'm from Wellington, I'm a pre-medical science major at Oklahoma State University, and I would say I'm a pretty lucky person, but for all the wrong reasons.

I've grown up as someone with PANDAS, and I've learned a lot.

Firstly, there's a lack of awareness and education on the disease. I lived 9 years of my life under the impression that I had Tourette's Syndrome and a fish bowl of other psychological disorders and nothing could help me. I had doctors tell my parents they shouldn't have high expectations for me. I had doctors tell me I was possessed, that I should find god, have an exorcism. I had doctors throw their arms up and say "I don't know, I can't help you". Imagine an elementary schooler being told they wouldn't amount to much, or that they had a mystery disorder. You're looking at the person who dealt with all of that.
The day I was finally labeled a PANDAS patient. I was already done with 15 years of my life. That's all of elementary, all of middle school, and most of my freshman year of high school. 15 years of experiences that were never quite "normal" and man did it suck sometimes to not be "normal". It was luck that we found Dr. Kobayashi. Not as lucky that he was 330 miles away, but I'm beyond grateful that I was accepted as one of his patients but I always wonder what could have happened had I been correctly diagnosed at a much younger age, and I feel the same for the thousands of other kids dealing with the same problem. It all comes back to education.

Secondly, I learned that not everyone is willing to adapt and work with people who are different. One sparkling example of this would have to be my elementary music teacher. Music class is supposed to be a fun break from school. To be frank, it was hell for me.
I had many vocal and physical tics, I would yell randomly, I would throw my head back violently, clear my throat, flick my wrists, stomp my feet, slap myself in the leg, all of that. Despite my parents best efforts to educate the school staff on this. My music teacher took exception to my existence. I remember being isolated in front of the class, told to cover my mouth or leave the class, and then sent to the back corner of the room. Nearly everyday. My second grade teacher was no better. I spent every single day of that school year serving time after class for "outbursts" aka my vocal tics. Imagine trying to read quietly knowing full well that you can't go 10 seconds without making a noise, but knowing if you do, you get in trouble. Picture yourself taking an important test. You need to focus but you're anxious about getting the answer wrong. You try to read the questions but you have to squeeze your eyes shut every 20 seconds. When you are finally able to read the question, you can't write the answer because you have to tap the desk exactly 16 times every time you pick up your pencil. Other students are giving you angry flares because while all of this is happening, you're also bouncing your leg off of the floor. You get up to finally turn your test in right before time is up, but you have to brace yourself before you go because you hate when people stare at you, and you're convinced that everybody will stare at you. In the end, your teacher walks by and takes the test off your desk instead, remarking that you need to be quieter next time as she moves past you. That was my life for the longest time. And the questioning looks didn't stop as the years wore on. But I make a point to explain PANDAS to anyone who throws me a sideways glance for twitching my eyes. I highly doubt my experience in this regard is much different than anyone else's who grew up with this disease. It hurts to think about how many kids are going through this. After all, up to 1 in 200 kids have it. There's over 50,000 kids in Wichita alone. Think about that. Think of the students getting bad grades simply because they can't function enough to sit down and do schoolwork like a typical kid, even though you just know that they are smart.

Third, I learned that sometimes the best things happen at the worst times. With PANDAS, you go into "flares"-- days to months long period of severe symptoms not normally observed. Not too long after I started seeing Dr. Kobayashi I fell into a flare, vocal tics came back, my OCD was unbearable, and I was generally not feeling good. Around the same time though, we learned I qualified for a study. I would get 6 rounds of a treatment called IVIG, which had showed to be effective in battling PANDAS. The first couple rounds were brutal. I had to quarantine both before and during the treatment because it was flu season and missing a treatment could have made me ineligible to continue. I missed out on fall sports, theatre, and marching band. We drove 6 hours one way so I could sit in a room for 6 hours with an IV in my arm. Every three weeks. It scrambled my brain for awhile, I felt like nothing was getting better, only worse. I would do it all over again though, because it was like somebody snapped their fingers and it started working. The following four months of my life were the best I ever felt. My anxiety was gone, my OCD was gone, and my tics were at an all time low. Though they came back for a while after treatment ended, slowly but surely my symptoms have mostly gone away again. IVIG is astronomically expensive though, and had I not been apart of the study, there's no way I could have received that treatment. I want you all to think about the possibly 2500 families in our state who may be facing the possibility of never finding treatment for their kid because they can't afford to. What if it were your kid? Wouldn't you do anything in your power to help them?

I am lucky that my family was determined to find an answer. I am lucky that we live juuuussssst close enough to Omaha for me to be a patient. And I am lucky that I qualified for the IVIG study. Without it I wouldn't be on a full ride scholarship, a Kansas Governors scholar, or the former president of my drama club, my choir, drum major of my marching band, and captain of my scholars bowl team. All of these achievements came after IVIG, and I'm just imagining all of kids who can't get to this point without it, for all the wrong reasons. There shouldn't have to be luck involved for there to be a PANDAS success story. Look back at what I've just told you about my life. Could you make it to where I am, dealing with all of the things I dealt with? Maybe. Would you want to? Surely not.