My PANDAS Story

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My PANDAS Story: Foreword

Hi, I'm Hudson. I'm 11 years old. I have PANDAS. And I never liked feeling like I was the only kid out there that had it. So, I wrote this book to help other kids like me to feel like they weren't the only ones. I also wanted to know that there were other kids that had bad and scary thoughts like me, and not a lot of people liked talking about that part of PANDAS, so I didn't find much comfort. I hope it's the opposite for you! I hope reading my book and learning that I've overcome PANDAS several times will help you be less afraid that you won't overcome it.

I'm a kid, a normal kid. Well, at least that's what I thought. I like running around, doing school, and I love my mom and dad!

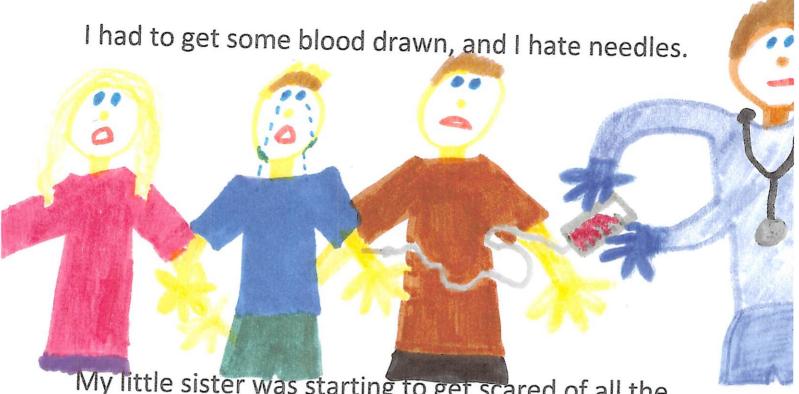


One morning I woke up and did not feel the same. I had a terrible thought in my head. I started to get really anxious and worried. I told my mom and dad.



I started having lots of bad, inappropriate and mean thoughts. I started having a tic where I couldn't stop poking at my eye. We wanted to know what was causing these changes in me, so we started seeing doctors.





My little sister was starting to get scared of all the doctor visits and how differently I was suddenly acting, so one day we took her to my Gramma's house instead of to the doctor with us. My dad described my symptoms to my Gramma and while my mom and dad and I were at the doctor's appointment, my Gramma looked online and found an article about a disorder called PANDAS. PANDAS stands for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep. I had a bad case of strep 4 months earlier, and the symptoms for PANDAS were exactly what was happening to me!

Here are just some of the symptoms of PANDAS:

Sudden OCD (mine was called Bad Thought OCD)

Severe Anxiety

Physical Tics

Drastic Mood Changes

Blurry Vision

No Appetite

Changes in Handwriting

Needing to frequently urinate

Math becomes much harder

Can't control what you say

Feeling bad about yourself/not believing it's a disorder

New Phobias (of germs in particular)

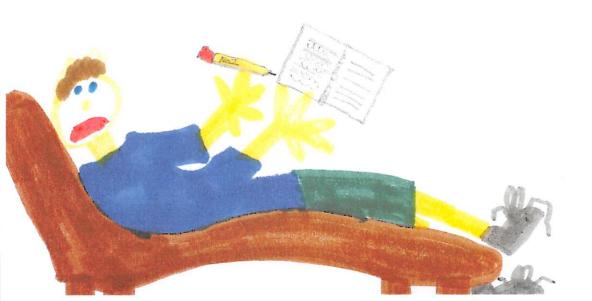
Separation anxiety

Can't focus or make decisions

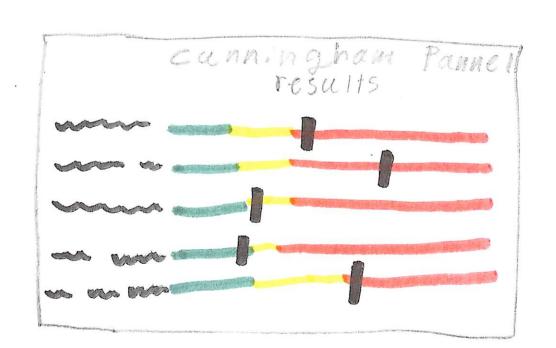
Once we learned about these symptoms, we were pretty positive I had PANDAS, so we went to another doctor and asked if she had heard of it. And lucky for us, she had! She said we should go to Jay Jeter, a therapist who also knew about PANDAS. So we started going there.

I told him my bad and inappropriate thoughts. He told me to write them down in a journal and then let my mom and dad read it (this also helped so my little sister didn't have to hear my scary thoughts). I also started to get freaked out about germs, which he helped me calm down about.

The therapist helped me deal with PANDAS better, but he couldn't treat it, so we kept looking for good doctors that could.



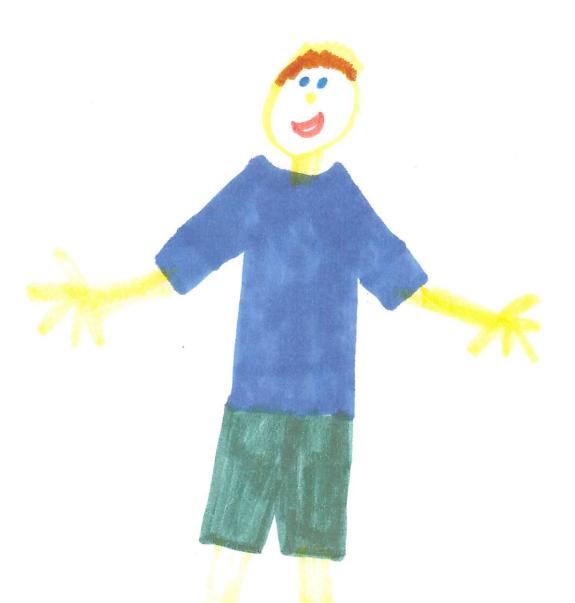
After more research, my mom and dad found a doctor named Dr. Infante. He knew a lot about PANDAS, but we couldn't get in to see him for two months. So they kept looking. Then they found a doctor named Dr. Rao who could see us right away. He lived in Plano, five hours away, but he knew a lot about PANDAS so we went to see him. He wanted to draw some more blood from me to do a test called the Cunningham Panel. This test proves if you have PANDAS, so I did it. He said it would take a while for the results to come in, maybe even a few weeks. A couple weeks later, we got it. It said if one of the markings was in red, you have PANDAS... and mine had three in the red! So, we knew I had PANDAS.



There is a treatment for PANDAS. It is called IVIG. It only takes a few days. What PANDAS does to your mind is, when you get sick, especially with strep, your antibodies attack your brain instead of the sickness. But IVIG floods your body with new, good antibodies that force the old ones to leave, so your brain isn't getting attacked and your PANDAS symptoms can start to go away.

We scheduled IVIG with another doctor named Sid Atkinson. I had IVIG done over two days. It was not fun, but I slowly started to feel better! After four months, I was 100% worry-free and back to my old self again! I was good and healthy and worry-free for a year and a half. Then one day, the symptoms came back. Each time PANDAS affects you, it's called a PANDAS flare. We knew I was in a PANDAS flare, so I got IVIG again and just like the first time, it worked! That lasted for another year and a half. Then, I started having symptoms of PANDAS yet again! So, I did another blood draw for the Cunningham Panel and the results proved I was definitely in a flare again, so I got IVIG for a third time.

Now, I'm slowly healing again. And one day, I'll be good as new!



^{*}Sometimes other things *besides* Strep cause these same symptoms, so when that is the case it is called PANS. Pediatric Acute-onset Neuropsychiatric Syndrome.