

Fall of 2014

The fall was going great. I took my mom to eat and she needed to get her shingles and flu vaccine and figured since I worked at the college I should get mine too. So we were multitasking on a weekend of the first November..

It was a week into November and I was working as usual as a part time assistant at the local community college. I will never forget when it started. I was grabbing some files for my boss when I squatted down and came up with a head rush. I came up and thought, wow I feel dizzy. The rest of the day I was kind of off and not myself. I told my husband that I had a headache and felt off with my vision. I was honestly scared of having an aneurysm (truthfully, I have always been the one that goes from stomach ache to stomach cancer.) Anyway, the next morning, still not feeling myself, I went to a redi clinic and that's when they said I had an inner ear infection prescribing me 5 days worth of antibiotics. After the third day I was like I feel better so I'm good no need to take anymore. I went through Thanksgiving wondering if in fact I should have gone to the ER because I was still having a headache so I ended up going in which they did a ct and it was normal.

Honors day at the college was December 5th. I was happy to get that day over with as honors day is crazy but I felt good , no more headaches and I was really loving my job! It was right after lunch that the headaches returned. I thought to myself, maybe I am stressed and just need a drink. I couldn't wait to get home and have a drink with the hubby in which I picked the kids up headed home and relaxed. I grabbed a beer and opened it but funny thing is, it didn't taste the same. I then was like, ya know what, I don't want this. I just want to be normal. Over the christmas holidays I started seeing a neurologist in the woodlands, I kept telling her something wasn't right but after 4 or 5 visits and numerous ct scans and MRI's there was NOTHING. Still so upset I contacted my primary doctor who wanted me to start seeing a psychiatrist or psychologist and gave me a script of lexapro. On my last visit to the neurologist, I was waiting for the neurologist and sitting in the chair I looked up and a thought came over me, that I should stick my hand in an outlet. I shook in my body, like what is wrong with me. I left and never peeped a word. Just taking her saying , 'you need to see a chiropractor' , was the answer and I had occipital neuralgia.

January came and I had a constant anxiety to go to work and hated to be there. I developed what I call a "personality disorder." I was mean to everyone, my kids, my husband, my boss. I then told myself I was probably bipolar as did my doctor. I called my primary many times only then with them saying in nicer words, that I was crazy and to go see a psychiatrist. I started seeing a counselor when I got off work and tried to handle life. Well one night asleep with my husband I woke up with a thought that I would hurt my kid. I then panicked, got in my car and went across town and banged on my moms door begging her to pray with me. She prayed with me and told me I would be okay. The thoughts persisted and were disheartening after all I loved my kids. When my husband would leave me home with the kids I would freak out. I told my counsellor but he said it was normal and that I had OCD HARM THOUGHTS. He also would

continue to help me with therapy. I soon quit my job and was constantly confined to the house. Shortly after my Mother had a stroke and I started working from home..

I tried to cope the best way that I could without anyone knowing what I was facing and was told to maybe have my hormones checked so I paid about 500 dollars to have my hormones checked and soon learned I had a genetic gene mutation, so we tried to do methyl b 12 and progesterone. With no results and as frustrated as I was I started working out harder and meal prepping. I could no longer use knives in my own home and I hated to see guns. I could no longer watch scary movies and life was spiraling out of control. I went to a HERs clinic where they told me my progesterone was low and testosterone was too. I was so terrified to get put on testosterone because of the fact I still sort of thought I was bi-polar. I was working from home and hated it but got paid pretty good. I then thought I had some serious disease and would NEVER be able to go work for anyone again. I then started researching hormones and figured maybe since I had my tubes tied, I was suffering from tubal ligation syndrome.so I talked my husband into getting the tubes untied and it wasn't cheap and we had to travel. We had my tubes untied in November 2016. While it was great to get away and feel like maybe I had finally figured out the piece to the puzzle, it still wasn't right.

Fast forward to 2018, still no real improvement but I was able to just get through my day. I stayed away from the house a lot and my sleep since all of this has been max at 5 hours a night. Chris , my husband would always ask what's wrong where is the Robin I used to know? I would just cry and be like that day at the college I don't know. I dont know whats wrong with me, sobbing and praying and Wondering what's the hell happened!?!?. He's a good guy yall and he has been through hell with me. So April my 12 year old daughter was having an issue with 13 girls who got caught drinking at the school in which I was tired of her being harrassed so I ordered a meeting with the mom. We had just returned from San Antonio the weekend before and I wasn't feeling good. Thinking I could be pregnant, I bought several tests and sure enough we were. Due January 12th of 2019 it was awesome. I started working part time for my brother doing web support and quickly found a love for it.

December was here and I had less than a month, but near the end of the month Chris told me something that didn't sit well with me. He told me my oldest daughter had told him she was having bad thoughts. He said he told her sometimes when you go through a lot you just get tired and frustrated. So he just told her she would be okay. Riverlee Graye came about 822am January 12th. She was perfect!! Everything was perfect.

It would be in April my thoughts started to come back for about a month and all I told a lot of people was it was post partum! The thoughts would stick and replay in my head. I felt like a criminal. Summer time came and I loved it when my kids would stay with me at home, they are so funny. They were always a lot of help. It was the end of May, I took the kids to the dentist and they had cleanings, fillings and Egypt needed braces. That weekend she wasn't feeling well and told me she had a nightmare her sister was murdered. I just prayed and told her she would be okay.

It got really real. Her nightmare trickled into thoughts. I was like what in the world is happening???! First me, now my baby!! I googled all night and saw that she was possibly having a strep induced disease PANDAS/PANS aka (Autoimmune Encephalitis.) I found a mom who offered to call me and we talked and talked and she assured me it was PANS. I cried everyday, I still do. I made an appointment with a doctor in Magnolia whom so many people love and his staff assured me he knew what PANS/PANDAS was. I went in at 7:30 am and saw him and he said strep was negative and that she needed to see a psychiatrist. I cried because as a mom you never want to hear that. I did find a psychiatrist in Bellaire. In the mean time I saw others on <https://latitudes.org/forums/forum/> whom found supplements that worked. We started on CBD oil, NAC, probiotics, Ibuprofen, melatonin, and others. She also had a wonderful teacher that provided her with books to read. Unfortunately, I also met a lot of people who became non-believers when this happened to their kids. If anything my faith has gotten stronger. I started taking her to counseling and some days I wondered if I should take her to a facility. I then found a pediatrician in the Texas Children's network that agreed to see her and he assured me that he would figure this out. However it was taking forever and I needed answers. I finally got her into a doctor in Webster, and she ran tons of tests on her. It was the Friday before school started, She called we listened. Egypt's Mycoplasma levels were 4100 plus!!! My kid has mycoplasma!! She wasn't crazy. I was still trying to get in to see a specialist in Katy but his office said I needed a referral.

The next 2 weeks she was to be on bactrim in which did nothing. My son had just been seen as well by her and also came back with high myco-p. So she told me to in fact get his body prepared to take bactrim as well. After talking to lots of others, they said that is not standard treatment at all. I called the doctor with literature from biochemist Dr. Garth Nicolson, who talks about the smarts of mycoplasma and you must use Azithromycin for 6+ months to even see or notice a difference. When I called the doctor she got snippy with me and just said she was going to treat her with this and it just takes a LONG time. I agreed and just hung up and cried knowing this wasn't working. I emailed her first doctor in upper Kirby area and he called me that night. I had also emailed him a copy of my daughter's numbers in which he was shocked to see such high myco p and asked if an infectious disease specialist had gotten in touch. I said no and told him who I was trying to see and it had to be God then, because with excitement in his voice he said hey I know him, let me make some calls and get you guys in. They called me that afternoon and has me scheduled for the end of September.

October 2nd, We saw the neurologist. I was excited and scared. He looked at her numbers and immediately put her on azithromycin for 2 weeks then a week off and then would order more blood work and see her again to assess. He also advised that we all be tested. My OBGYN went ahead and ordered a test and sure enough I had it. Could it be I wasn't crazy all this time? I felt so many emotions like why is this happening but in a good way was relieved that I wasn't crazy, that something was going on with me. We followed the protocol and her numbers didn't even move. When I went to the follow up appointment, I told him about my numbers and he placed her and I on Augmentin. He also scheduled her for IVIG but the insurance has denied it.

They have also denied her braces. This is a very serious illness. Her mind isn't what it used to be. I miss my kid. The one who loved her brother. The one that wasn't scared to go to sleep. She doesn't sleep much. She is scared of her thoughts. Yes I co-sleep with my 14 year old. Yes, I am scared, Yes, Some days I have no idea what I am doing. Yes, I am frustrated and I hate the insurance companies. Sometimes I wonder if the vaccines had anything to do with it. Sometimes working on my dads property I wonder if we got bitten by something. I don't know.

My son and I have a follow up with this doctor next week, I am scared and frustrated. I know God will see us through. Why should a kid be tormented by their own mind? And have I possibly genetically given this to my kids? My husband will be the last one tested. I don't ask for anything but just prayer. God has shifted us, moved us and given us an opportunity to share this story because a lot of kids' stories are untold. I am mad at the medical system. Six months ago, I contemplated placing my kid on psych meds. She is still growing and needs to have a pure mind and a fresh mind. How could I do that to her? Looking back now there were so many symptoms I never saw, she had nightmares, throwing up after meals for no reason (chalked it up to acid reflux), consistent bathroom usage, and always changing clothes. The OCD and the thoughts are the worst. It takes her about 10 minutes to brush her teeth.

Unless you have ever had intrusive harm thoughts before, you'll never understand what it is. My life is so busy these days with our baby girl, if I am not up with the baby I am definitely up with my oldest. I worry about the finances because IVIG has been denied so far, and her braces have been denied twice as well. I will fight for this no matter what and will always do what I have to, so that my kids have a better healthy life! Just how God's love doesn't give up on us, I will not give up on my kids. I won't lie, it's frustrating. But for whomever needs to hear this, Mama, you are doing a good job and you are not going unnoticed!