

Hi everyone! My name is Katie Long. I'm a 37 year mother of two awesome teenagers in South Carolina. I was diagnosed with FMD in 2012 after a series of strokes.

The last thing I ever saw clearly was my friend's daughter's laughing face at her three year old birthday party. Her birthday happens to be perfectly poised to fall on Labor Day weekend, and her birthday parties are a blast for adults and kids alike. We had been swinging into a huge foam pit, and we were having so much fun that the party ended up running two hours over. To this day I still wonder if the swinging led to what followed, but the doctors never really had an answer. After the last swing in I was helping my friend's daughter out of the foam pit when the aura and headache slammed into me at the same time. I very gingerly got out of the pit and called my kids and their friends together; I told my friend and my sister that I had a migraine with aura. My friend, being also a life long migraine sufferer, knew right away how I felt. I didn't know how to put into words how different I was feeling, how the world didn't feel right and nothing made sense. Or how my mouth had already gone numb on one side and I couldn't feel the left side of my chest.

We packed up the cars as fast as we could. By that point my nausea was nearly overwhelming. Somehow, I got my children's friends safely to their homes and at our house I remember emptying the dishwasher. My daughter asked me for help with her math homework but I couldn't make sense of anything. My sister told me to go lay down, that she would help her, and I stumbled to my room in a painful haze. My fiancé came by and was concerned enough that he felt I should go to Urgent Care. Now I had had migraines with aura my entire life, but I had never needed to go to the doctor for one.

By the time we got to Urgent Care the numbness had spread from the left side of my face, down my chest, to my left hand. It actually hurt to think. The doctor diagnosed me with a super migraine, gave me a shot of pain medicine and told me to stay home from work the next day. The shot took enough of an edge off of the pain for me to eat a few bites and then pass out in a strange haze at home. My daughter was 10 at the time and very much in the habit of sleeping with me. That night she woke up because I was mumbling and shaking, she called my fiancé and told him I couldn't talk right, that my words weren't making sense, and something was seriously wrong. He came right over and took me to the emergency room. Where we sat for nearly four hours before being seen. By then the numbness was at my hip and they wheeled me back in a wheelchair. A CT scan was ordered, and I was told, again, that I was just having a super migraine. More drugs, and three days off of work this time. I spent that entire day in a haze. I remember my TV was on Nickelodeon and Spongebob played all day. I didn't have the energy or mind frame to turn it. Thankfully, I have an awesome sister, she took care of my kids and me, and I was just waiting and hoping the pain would pass.

That night when I got up to use the bathroom my leg had gone numb. I remember looking down the hallway towards my sister's room thinking it was a million miles away. Leaning against the wall I dragged myself down there and threw myself through her door. She quickly called my parents. They were there in five minutes and my dad took me back to the emergency room. Where we sat again for three hours. This time though they ordered an MRI. I remember the guy saying it would only take twenty minutes. I drifted while I listened to the music they played. Then the guy came back and said it would be another twenty minutes. And that was when I passed out. Hours later I woke up in a hospital bed covered in monitors, IV in each arm, and my parents staring at me with tears in their eyes. The doctor came in and that was when they told me what had happened. I had had four strokes, the initial headache was the beginning, and first stroke, also the one that had damaged my eyesight. I was 34 years old and I had had four strokes. Two in my left lobe, one my right and one in the thalamus. Even the nurses kept saying I was the youngest person on the floor. Yay:/.

At that point they had absolutely no idea why I had had the strokes. I was in the hospital eight days and finally they ordered an Arteriogram. Generally done sedated I had to be fully aware because of the strokes. The nurses argued with each other the whole time. I was laying on this table with a doctor sticking a line through my femoral artery and these two can't get it together. The neurologist came in to diagnose me with this crazy disease no one had heard of Fibromuscular Dysplasia. What. Ok, so what now?

Shockingly, I was able to fully recover physically, with the exception of the tips of my fingers. But my scrambled brain couldn't unscramble my eyesight. I tell people it's like watching TV on a bad channel all the time. If you have migraines with aura then you can understand, that's how I see permanently. Sometimes when I look at a sidewalk my brain wants there to be people there so I see ghost imagines my mind has "created." In rehab they told me it's the brain trying to compensate.

At my job I was the boss and the human resources decided that my medical condition wouldn't allow me to do the job anymore so I wasn't asked back after my six month medical leave. That was a blow because of how much I had put into the company, but with my eyesight being what it is I do understand. But a former boss offered me a new job so I went back to work.

Even though migraines went from a passing nuisance to a weekly problem, and I had to take Plavix daily and learn how to deal with seeing the world differently, I was feeling like I was becoming me again. Fast Forward a year and a half. I was headed to work one day when I suddenly got a mind numbing head ache, overwhelming nausea, and my hand went numb:(. I happened to be right next to an Urgent Care off the interstate so I went there, because there was no way I was going to make it to the hospital. I stumbled to the counter and told the lady it was an emergency, I had a history of stroke and had all the symptoms of another one. And she told me, "Stroke or not you have to wait your turn." I broke down, hysterically I called my sister and she told me to call 911. So I did, they were confused why I was calling from Urgent Care, but by the time I got to the hospital I was convinced I was wrong. I had just started a new medicine and thought that I was having a bad reaction.

Unfortunately I was wrong. The doctor said he was sorry, he could see the other four strokes, but this one was still developing. This one landed me in a rehab facility. By the next day I had problems swallowing, and even now without spellcheck writing can be a serious issue. This stroke hit on the right side again, and I had to be retrained how to walk. I had to eat my food pureed like baby food, because I couldn't swallow right. I think the weirdest thing was that my hand wouldn't write what I wanted it to write, the connection from my brain to my hand was screwed up. Anyway, I loved rehab, except being watched taking showers, seriously, I no longer have any shame, lol. The therapists and doctors were all so wonderful and kind, and helped me tremendously, even with deficits from my first strokes.

When I have headaches now I sometimes go numb. I have to go to the hospital every three months or so because I'll get one so bad we just aren't sure and all of my doctors say I need to go at the first sign of a stroke. I have started seeing a specialist now for FMD. I have bilateral Vertebral FMD. All my doctors say the same thing, they don't understand why I have had five strokes. They are definitely from the FMD, but five is excessive. With each one my vision gets worse too. Three of the five have happened in my occipital lobe. I went from being a perfectly healthy person with a great job and high energy, I loved to jog and go on adventures with my kids. To taking thirteen different pills a day to stay afloat.

After my last job didn't extend my FMLA, I applied for disability. It's a lie that everyone is turned down the first time. I was approved fast. That made me sad, actually, I didn't need an attorney or anything. I was just sick enough. I just turned 37. I have no intention of this being my forever. I still think that I can get my health under control and get back out there. There is way too much life left in me to wait around to die. The bad part about having a disease nobody knows or

understands is that people look at you and think that you look ok, you must be exaggerating. But on the inside FMD makes you feel like a Jackson Pollock painting. I think its weird when the doctor tells me my blood needs to be as thin as possible. I think its sad when I wake up and just want to go back to sleep. I hate that I move in slow motion because I don't have the energy for anything else. But the absolute worst part about all of this is on my good days, when I forget for a while and live my life normally, because for a moment I feel ok, I end up paying for it with a monster of a migraine. Or I sleep for two days. Or i end up in the hospital.