

NMOSD WON'T STOP ME: BROOKE STORY VIDEO TRANSCRIPT

Brooke: I'm a mom, and I'm a wife. I work part-time at a church. My husband, Eric, we've been married for 25 years. And we have one daughter, her name is Ireland. I remember when she was born, I was very excited to bring a baby into this world.

At six years old, Ireland started to have something going on. We'd be at the store, and she would just suddenly not be able to walk. I would actually just end up having to pick her up and put her in the cart. And I thought maybe it was just a kid thing, but we kept seeing it happening.

Then the other thing we noticed, in the mornings, she would sometimes scoot down the stairs on her bottom instead of walking down the stairs. And I was like, "Why is she doing that?" But I didn't put it together that there was maybe something happening. It wasn't until she started waking up in the middle of the night with terrible, terrible back pain and burning in her back. We ended up taking her to the E.R. the first time it happened. They sent us away. They thought it was something maybe GI related, because it was such bad back pain followed by vomiting. We didn't get many answers.

Probably about six months later, the same thing happened again. She would just cry and scream. It was as if somebody was stabbing her in the back, and there's nothing I could do about. I took her to the E.R. again, but I just knew that there was something else going on, way worse than what they told us.

Actually, at that time I felt like maybe there was something on our file that said, "These guys are crazy," because I did end up going to another doctor. And before I even really had a chance to talk to him, he told me that I was being obsessive, and I was so, just, at that time so defeated, because I couldn't get anywhere. I knew there was something wrong with my kid. I felt like they were looking in the wrong direction. And now I've got a doctor telling me I'm being obsessive, which makes you, you do feel crazy at that point. "Am I being absolutely insane?" You know, "Am I being crazy that I'm trying to get somewhere with this, with the diagnosis, you know, for my child? Am I making this up? What is going on?"

And then she has these other times where she's able to dance. So it was like this back and forth a lot. And we ended up going to a dance recital. And then the next morning, she came to my room, and she said, "Mom, it looks like I'm looking through like water, and just in one eye." She said it was painful. I ended up taking her to an eye doctor that day.

And they knew right away that something major was happening. They could see that she had inflammation behind her eye. She was seen by a neurologist, and they did an MRI then and they were, they saw all the damage. So they saw that there was lesions on the brain, the lesions on the optic nerve, and then they were able to see that she had lesions all the way down her spine. And then this neurologist, he ended up sending her blood away to be tested, and it came back that she had neuromyelitis optica.

Onscreen text: Neuromyelitis optica spectrum disorder, or NMOSD, is a rare, lifelong autoimmune disease caused by inflammation of the central nervous system, which is made up of the optic nerve, brain and spinal cord.

Brooke: And I got on the internet, and started looking to figure out what this is. And right away, you know, I saw all the statistics, at that time, for death and paralysis. And I just remember breaking down in front of the computer and feeling like we were living a nightmare. I remember she was like, "Mom, is this going to kill me?" You know, what do you say to that? I'm like, "No, no, honey, it's not going to kill you. It's not going to kill you." It's all we could say. I still believe it. I still believe it. It's not going to kill her.

Onscreen text: Doctors began treatment on Ireland immediately to help manage her NMOSD symptoms and prevent further relapses.

Brooke: Once she started medication and stayed on it for a bit, she did become stable, eventually. It really took maybe a year, for us to start to trust that maybe things were going well. She still has issues, but it feels like we're headed in the right direction. The further away that we get from those flares, we just see amazing things happening.

It feels pretty natural as a mother, to be a caregiver when they're young, and even as a teenager. Now it's a little harder, but I think it was pretty natural just because you're a mom, you're a caregiver, you're, it's just part of the job.

Overall, she's been doing great. She's had a lot more trauma and heartache than other people have experienced. And you can see that she's come such a long ways, and she's an incredible adult, an incredible human being, and kind and compassionate. And now she cares about others that has the same disease. And she wants to help others. The medications and the things that are available for people with NMO, even though you're given this diagnosis, and even though the Internet may say all these awful things, have hope and believe, because we've seen really amazing things happen. And I'm so grateful for it.

Onscreen text: Hear more unstoppable stories and learn more at NMOSDWontStopMe.com