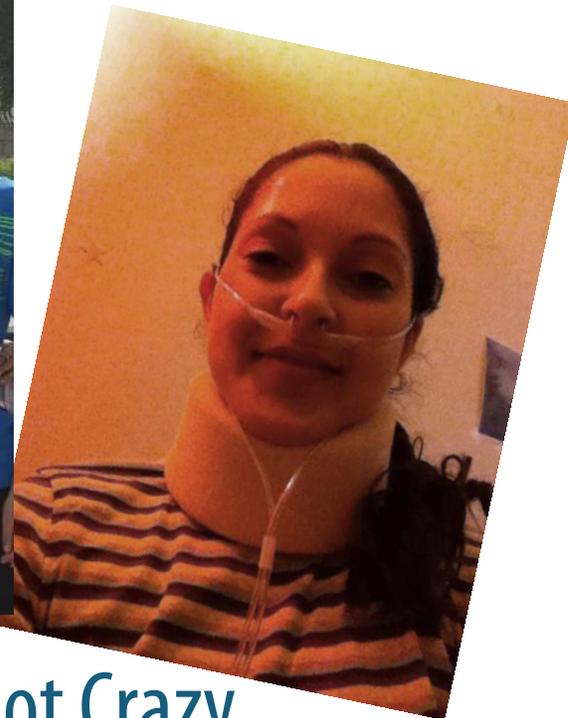


Our Story



HHT is Real, You are Not Crazy

By Lauren Linhard

Since JJ Zazueta's middle son, Matthew, was 6-years-old, she always knew when he was awake in the morning. There'd be a sudden thump as he launched off his bed, a scurry through the hall, a slam of the bathroom door and the sound of running water as he let his nose bleed down sink.

"He's 17 now, and still leaves every morning for school with clots of tissues up his nose," JJ said. "He's so angry, and hated that I got him tested. But I'm thankful he and my youngest, Anthony, have been diagnosed so we can find the right treatment."

JJ, who was recently granted full disability, was diagnosed with HHT at 35-years-old in December 2014, even though her symptoms began when she was 10-years-old. She was known as the girl who'd pass out in the hall between classes and was often seen running to the bathroom with her nose gushing blood.

It was just luck, JJ said, that she had a group of friends who stuck by her during those bad days, even carrying her home when she couldn't walk.

"I remember my mom would find me in my bed, covered in blood when she came to wake me up and totally freak out," JJ said. "I guess it's ironic the same thing happened to me once when I went to get Anthony out of his crib."

"Crazy" was the word most often used by doctors in response to JJ's complaints. She recalls doctor upon doctor telling her everything was normal, that there was a totally legitimate reason for the blood clots coming out of her nose, the mini seizures and the memory loss.

Even when she brought a giant blood clot to her OBGYN as proof of her symptoms, the doctor maintained such things were a common occurrence during pregnancy. Consequently, JJ almost bled to death during each delivery of her three sons.

It was the doctor called to the stand during JJ's disability hearing in 2014 that finally put all the symptoms together – they were effects of HHT, specifically of untreated AVMs that have almost taken over her entire liver.

This discovery came on the back end of five traumatizing years during which JJ was hospitalized four times. Doctors didn't know what to do with her, she said. One second things seemed to be going fine and then her heart would give out, and the next second her lungs would collapse.

"There have been a few times where my kids have had to revive me at home with an EpiPen," JJ said, who also suffers from regular seizures, muscle spasms and long term memory loss. "I'm sure there is brain damage of some kind."

The only bright light at the end of this long tunnel was finding Cure HHT, JJ said. Though it's terrifying to have HHT, learning from the webinars, website and HHT doctors has empowered JJ to take what steps she can for her and her family.

JJ is actively seeking HHT-educated physicians to work with her sons, and both Matthew and Anthony go to school with their Cure HHT Patient Symptoms cards in their backpacks. It's often the little changes that can make a big difference, like reminding yourself not to blow your nose so hard or to carry a mister to keep your nostrils moist, JJ said.

One of the biggest steps of all, though, was the day JJ took a deep breath, held tight to her resolve and called Cure HHT asking to share her story in the hopes of helping someone out there who has gone through similar issues.



JJ's Daily Dose of Supplements

"You are not crazy, and what you are going through is not normal, no matter how many doctors try to tell you it is," JJ said. "If I can help somebody by having my whole life turned upside down, then all this is worthwhile."

Donations to Cure HHT can be sent to:

Cure HHT

PO Box 329

Monkton, MD 21111

Or by clicking [here](#)