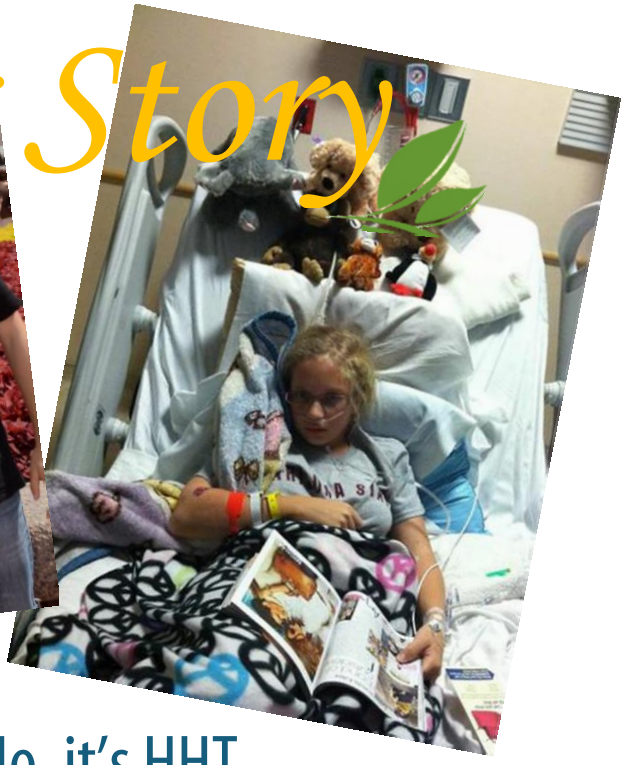
Our Story



It's Asthma. It's Pneumonia. No, it's HHT

By Kristi Pahnke

When my daughter Hayleigh Pahnke was 4-months-old, she had her first asthma episode. I took her to the hospital where she received a breathing treatment for oxygen levels in the low 80s. The hospital didn't think much of her numbers, saying the equipment wasn't made for babies so it wasn't accurate. Being new to this, I assumed they knew what they were doing.

In the next year-and-a-half she had quite a few more asthma episodes, and every time with readings in the low 80s, and every time the hospital blew it off.

When she was 22-months-old, she was sicker than I had ever seen her. She was lethargic and pale. She wasn't eating or drinking. She didn't even have the energy to cry. I made her an appointment with our pediatrician for later that day, but the more I watched her, the more I knew she had to be seen right then.

The waiting room in the ER was packed. I thought we'd never get in there. My poor girl was still very lethargic, and the only way she was comfortable was when I was holding her upright. If I laid her down in my arms, she would cry a very weak cry. So I held her for four hours until we were finally called.

Once the nurse hooked up the pulse-oximeter to her finger, it read 74 percent. I'll never forget seeing that number. The nurse thought for sure it couldn't be right so she put another probe on her, but got the same reading. The next few minutes were a blur as the room filled with doctors and nurses who started an IV, took x-rays right there in the room and prepped her for transported by ambulance to the children's hospital. She had pneumonia and RSV.

I was taken into another room where I could call my husband, Scott. I remember walking into the hallway and losing it. A sweet older lady, who was waiting for her husband to be examined, hugged me and prayed with me, telling me everything would be alright.

We got to the children's hospital, where it was confirmed my little girl had pneumonia (in addition to RSV). She was admitted and we spent the next week waiting for her to improve, but she never did.

She was on high doses of antibiotics that weren't helping the "pneumonia" clear up. She had percussion therapy, where they pounded her chest lightly with a little rubber tool to clear the lungs, three times a day. She was on 100 percent oxygen this whole time, but her levels never went above the low 80s.

Her red blood cell count was triple what it should have been and they couldn't figure out why. They did a bronchoscopy and suctioned out her lungs, but that didn't help either. They did the sweat test to check her for Cystic Fibrosis. It was negative (thank goodness), but they STILL couldn't figure out why she wasn't improving.

Finally they called in a cardiologist who ordered a CT scan. They found the problem. And it could be fixed.

The doctor said she had a pretty rare problem in her right lung - a large pulmonary arteriovenous malformation which was causing her oxygen to be dangerously low. He sat with me for a long time explaining what it was, what it was doing to her and how they were going to fix it. She was scheduled for a cardiac catheterization and an embolization.

The next day came and we got to walk her down, and hand her over for surgery. That was one of the hardest things I have ever had to do. My husband and I waited for what seemed like forever until we finally got to go down to recovery. Hayleigh was not a happy girl, but for the first time I noticed her lips were pink. I had always thought that grayish-blue color was just her. That's how she had always been.

The next day, she got to come home. It was so nice to be home, and it was even nicer to see how much more energy she had. We always thought she was just a quiet girl. But she changed! And it was good.

We got a call from her cardiologist a couple of days after her release saying that he wanted to refer us to a geneticist because PAVMs don't usually happen without a cause and can be linked to genetics.

They looked Hayleigh over from head to toe, found some telangiectasias, took pictures and documented everything. She was clinically diagnosed with a genetic condition called Hereditary Hemorrhagic Telangiectasia (HHT). About a year and a half later, they finally came out with DNA testing and managed to find her mutated gene for HHT.

Hayleigh is now 15-years-old and has been diagnosed with type 1 diabetes, celiac disease and is consistently dealing with nosebleeds and GI bleeding from HHT. But she refuses to let these challenges define her. She is stage manager for the high school theater group, a proponent for rare disease awareness, a cheerleading coach, a sibling to two younger sisters and an older brother and so much more.

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