



Superheroes Come in All Sizes

By Renee Palmer

I am the proud Momma to an amazing 6-year-old daughter who found out she had HHT Aug. 10, 2013 - her name is Jozie Dawn. She was only 4-years-old and I was devastated.

I had Jozie looked at, screened, listened to and tested by the HHT Center of Excellence in Baltimore when she was 7-months-old. I was told then that she did not have HHT, although no blood work was done at the time.

Their father had only been clinically diagnosed with HHT previously, so when his genetic test showed positive for HHT, we made sure to get our children genetically tested. The boys' bloodwork came back negative, but my princess was officially diagnosed with HHT.

She had her bubble echo and CT scan done at UVA and both came back showing AVMs! She had two in her lungs and one in her brain.

That's when I met Dr. Kenneth Liu, neurosurgeon at UVA. He performed an angiogram Dec. 13, 2013, and suggested resection brain surgery. Only one month later, my little Jozie had the surgery.

They found a brain aneurysm associated with the AVM during the procedure, but my little girl miraculously came back to me the same as she was when I put her in their hands.

It was by far the hardest thing I have ever had to endure as a parent. I remember looking at my beautiful, amazing, resilient and seemingly normal baby girl thinking and praying they were wrong! Well, they weren't, and together we've been able to accept that.

Jozie spent three days and two nights in the hospital after surgery. She bounced right back with no long-term effects other than migraine headaches. Although they are debilitating, it's better than the painful reality that could have been her future.

She had coils put in her lung AVM in October 2014 at the HHT Center of Excellence in Baltimore. Jozie came out fine, but at her recheck CT they found five more AVMs. We are currently debating what, if anything, we are going to do with them now. They are small, but we wonder if they are causing the migraines. This disease always leaves me guessing and on my toes.

Jozie is my hero. She fights like a superhero and gives me motivation every day.

